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ABSTRACT

The book defines functional and categorical approaches to needs of developmentally disabled citizens, compares the current with the ideal service delivery system, describes approaches for effective advocacy efforts, and includes a resource guide for Californians. Seven functional definitions of such terms as self care, mobility, and capacity for independent living are followed by six categorical definitions of specific disabilities including mental retardation and cerebral palsy. Next, the concepts of individualization, normalization, and the developmental model are applied to seven in-home services such as respite care and in-home training; aspects of special education including instructional approaches, support services, and vocational programs; and different levels of independent living situations for adults. Finally, four kinds of advocacy (individual, parent-to-parent, parent-to-person, and group) are described in respect to needed changes such as reallocating poorly spent resources in community-based services and utilizing a hierarchy of tactics to effect change. The resource guide includes address lists for resource centers, area boards, and individual advocacy groups. Sample case studies are provided. (MC)

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SUCCESSFUL LIVING:

UNDERSTANDING CALIFORNIANS WITH SPECIAL DEVELOPMENTAL NEEDS

by

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DEDICATION

To Sheldon Singer, whose lifelong efforts to overcome physical challenges are a lesson never to quit and never to stop laughing.

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FOREWORD

Who Should Read this Book?

Successful Living is a book for people interested in fellow citizens who have special developmental needs. It is written for parents and siblings of handicapped persons. It is also written for high school and junior college students who would like to learn more about people with special needs and the services that are available to them. It is intended to serve as an introduction for people who wish to advocate for relatives and friends with special needs.

Special Developmental Needs: Learning, coping, and growth needs that go beyond what would be considered typical and that require extra services on the part of the service and social systems. This term is used to identify persons who were previously labeled mentally retarded or developmentally disabled.

Advocacy

Change is urgently needed. We are currently only doing a patchwork job of permitting people with special needs to act as citizens and contribute to society. We presently waste both dollars and human potential due to the ways we serve people with special needs.

People with special needs can benefit by speaking out for themselves and by help from advocates. The present system of services for people with special needs sometimes resists constructive change but consistent efforts by advocates can produce meaningful changes.

Consumer Unity

Many Americans, perhaps all of us, will need special services at one time or another because of a temporary mental or physical disability, or simply due to old age. If we look at what people need rather than at what they are labeled, we will find that all citizens share the need for a humane society with more efficient and decent human services. If society works for persons with disabilities, it will work for all citizens.

Normalization, Individualization, and the Developmental Model

All people born in our country are citizens with full rights. All desire life, liberty, and the pursuit of happiness. Even severely handicapped individuals can contribute to society as friends, neighbors, and producers of useful work. Everyone can learn and grow throughout life.

BILL

Bill works at a university research center. His friends enjoy his sense of humor and respect his intellect. His work centers on developing small computers to help physically handicapped people when they are shopping.

Bill was born with cerebral palsy. His parents were determined to help him have as normal a life as possible. They included him in all of the activities of their large family. Although they sometimes got fed up with the special care Bill needed, his brothers and sisters included him in their games and were proud of his accomplishments. It took Bill a long time to learn to talk. Because of damage to his nervous system at birth, Bill walks with a very wobbly gait. He went to special education classes in grade school and a speech therapist spent a lot of time teaching him to speak more clearly. These lessons were long and frustrating for Bill and remain some of his most painful memories. But today he can be understood by people who know him well. He still has difficulty making himself understood to strangers. Bill is considering purchasing an electronic aide to assist his communications with strangers.

Bill lives in his own apartment near a university campus. He rides to work on a three wheel bicycle. He is proud of his ability to get around town on his own - something that took lots of work. Bill is respected as a very competent computer programmer and specialist in special education. His first hand view of the needs of people with cerebral palsy are listened to carefully by his colleagues.

Bill has learned to accept the handicappist attitudes he encounters each day. He finds it particularly annoying to be talked to as if he is a little child. He is often angered by the difficulties people with physical challenges have in gaining access to the buildings and buses in his home town.

Handicappist Attitudes: Prejudiced opinions and emotions that many people have about people with special needs. Handicappist attitudes include the ideas that people with special needs are not full citizens, that they do not have their own thoughts and feelings, that they cannot be good employees, and that they should be excluded from normal life.

CHAPTER I. WHO ARE THE PEOPLE WITH SPECIAL DEVELOPMENTAL NEEDS?

This book is about people with special developmental needs. It is first and foremost meant to be about people - neighbors, relatives, fellow citizens. People who want the same things in life as most of us - a chance to learn and play, to live on one's own, to work and shop, to enjoy friendship and family, to have rest and fun, and to be healthy and safe. To read this book and make real sense of it, you need to constantly remember that it is the people, not their special developmental needs, which are first and foremost. It may seem like an insult to your intelligence to dwell so much on the concept of people, but in the world of people with special needs this idea is often lost at the starting line. It gets lost in labels and theories. Worst of all, it gets buried in prejudiced attitudes which permeate our culture. It is a sad fact that when most Americans think of a person with special needs, they begin thinking negatively. It is our hope that this book will help to change the way readers think about and relate to persons with special needs.

The word developmental has two meanings, a narrow and a broad one. The narrow meaning is that a person needs some extra help in order to accomplish normal daily activities during the first part of his life, i.e., between birth and age 22. This narrow meaning is a legal one. It is written into a federal law which defines who has special developmental needs. This definition is applied to decisions about who is entitled to receive special services. According to this legal meaning, a person who needs a wheelchair because of a car accident at age 35 has a special need but not a special developmental need. On the other hand, a child born with cerebral palsy, who needs a wheelchair to get around, does have a special developmental need since this person became disabled prior to age 22.

The special needs of all persons with functional limitations and the special developmental needs of persons who are diagnosed as having a developmental disability are often the same. If we think just in terms of what people need to live as independently and normally as

possible, then there is little difference between the needs of a person who must have extra help due to a disability that develops before age 22 and one who requires help as a senior citizen. Although people with special developmental needs usually will have them for their whole lives, many of us will experience similar needs for help for shorter periods. Thus, not only do we have the same basic wants and hopes as people with special developmental needs, but a great many of us will at sometime during our lives share the same need for extra help.

If we can satisfy the needs of people with developmental disabilities and those of other persons with functional limitations, we are more likely to understand our own needs if we should become temporarily disabled and those of our parent's when they are elderly. About 1/4 million young people will require some ongoing extra help to live independently in their own home or apartment, but another 8 million citizens will require similar help as a result of old age, injury, or illness, - which originates after age 22. Similarly, about 2 million people, as a result of conditions occuring before age 22, will always need some extra help to make a living. But millions of us will be temporarily unemployed. One out of 7 workers will at sometime during their working lives miss 6 months of work due to an injury or illness. The point is that if we support the provision of appropriate care for our fellow citizens with special developmental needs, we are all the more likely to find appropriate care for ourselves in times of need. A hospital that develops a physical therapy facility for people with cerebral palsy will probably have good services for a youth who breaks his leg at football practice. This book is about a special interest that is in your own best interest.

There is also a broader meaning for the term developmental. In this sense, a developmental need is what is required for a person to progress and develop from where she is now to a higher level of skill, knowledge, and ability. Developmental, when used this way, assumes that any person can learn and grow at any age. Like all of us, the needs of a person with developmental disabilities will probably change throughout their life. As a student, she may benefit from a special education class. After high school, an independent living program and support services for her own living arrangement might be appropriate. Developmental needs, from this point of view, are not bound by any age limit. People can always change, learn, and grow by building on what they have now to achieve something new. Using the term development in the broader sense, a

Physical Therapy: A medical treatment for people with difficulty moving normally. Physical therapy can take many different forms ranging from exercises on special equipment, to the use of whirlpool baths, to instruction in alternate ways of moving. Many people benefit from physical therapy including people with sports injuries, stroke victims, and people with special developmental needs.

carpenter who wants to become a contractor has a developmental need. She may require the help of extra training, books, and a license in order to advance in her career. In this sense the difference between a normal developmental need and a special developmental need is much more arbitrary than a simple age cutoff.

The way that we draw a line between normal developmental needs and special developmental needs says a lot about our values as a society. In early America we considered an education to be a special need. Only a few children learned to read. Now, by law, we expect all children to obtain a free, appropriate education. Prior to the last 50 years, the ability of workers to organize was considered a special privilege. Now it is a legal right for workers to form unions. Our values have shifted and we take public schools and unions for granted. Perhaps one day soon our values will shift so that we take it for granted that people with physical and mental challenges belong in our neighborhoods, workplaces, and playing fields; and that they, no matter how different, have a right to live alongside the rest of us.

Presently, our idea of what distinguishes a normal need from a special need includes a huge range of differences. Consider our public buses in most cities and towns. The doors open wide enough that very fat as well as very thin people can get on. They are also built so that very short and very tall people can enter. Buses stop long enough that quick athletes and slow people can get on before the doors close. If you look inside an average bus, you see an astounding range of people, old and young, well dressed and sloppy, educated and uneducated, all going someplace. But if you look at who cannot enter a bus you begin to see who we have decided has a special need. The young woman in a wheelchair cannot get on a bus. Her chair cannot climb the steps and the door of the bus is too narrow. The person who has not been taught to read or whose memory is very short cannot find the right bus to take home. And the young man who only gets paid 40 cents a day at an activity center does not have enough money to pay for the ride.

There are some cities in our country, and in Europe, that take the idea of public transportation seriously. All of the buses have wheelchair lifts. The drivers are trained to wait a little longer when necessary and to provide extra assistance to those who need it. In some places, even people with very severe physical or mental difficulties earn a wage that enables them to pay for bus rides. How we draw the line between a normal need and a special need says more about us, the line-drawers, than about people with disabilities.

The Same Wants As Most Citizens

People with special developmental needs want the same things as the rest of us. They want to be able to ride on the bus. They would like to live in their own apartment or with close friends rather than in a big institution. They would like an education and a chance to work. People with special developmental needs are not asking society for luxuries. They want the same basics that we all generally assume to be part of a decent life. The fact is that right now these things are denied to most citizens who have special developmental needs. Until recently we have excluded millions of children from public schools. Even with a federal law which gives all children a right to a free education, hundreds of thousands of youngsters are still not being served adequately. Most people with special needs are not able to buy or rent their own home or apartment. Over 60% of people with special developmental needs cannot find work. Many of those who do have jobs work in sheltered workshops where they make far less than the minimum wage.

This sorry state of affairs has a long history and is thus deeply rooted in our consciousness and our culture. For most of our history, people with special developmental needs have been treated very differently than their fellow citizens. They have usually been excluded from normal life. Thousands were sent away to large, isolated institutions. Doctors and other professional people told us that these people were helpless and possibly dangerous. Parents of children with special needs were made to feel guilty and hopeless. Children's books and folklore have characterized people with unusual physiques as evil, like Captain Hook. Slow learners have been routinely treated as objects of ridicule, from the time they were kept as fools in Medieval courts until our present day comic strips. The roots of our present situation run deep. It will take many concerned, knowledgeable and socially and politically active citizens to change the way things are now.

Stereotyping

We all think in categories about people whom we do not know. When you think of your cousin Bill, you think of one particular individual who happens to like sauerkrautwith his frankfurters. But when you think of a category of people, for example, poor people, you may form a kind of composite picture based upon your experience with poor people. If you haven't

had much experience with poor people then you probably rely on stereotypes that you have -picked up from conversations with friends, television, magazines and movies. These stereotypes are convenient mental devices for helping us prepare to think about or act toward unknown people. But they usually are not accurate. The inaccuracy of stereotypes about people with special needs is extreme.

It is most important to remember that there is a huge diversity amongst people with special needs. For example, when people are told someone is mentally retarded, they tend to think he looks different, speaks poorly, acts strangely and may even have sometime which is, in one way or another, contagious. The odds are, however, that a person who learns slowly, and is thus labeled mentally retarded, will look no different than you or I. In fact, you might ride to work next to him for years and never even suspect that he once went to a special class for retarded children. You might suspect he was a slow learner only if you saw him struggling to fill out a tax form or having difficulty conducting a job interview. And you might find these activities a little tough yourself.

Dangers of Labeling. There is good evidence that if a person is given a label - retarded, crippled, handicapped, blind - other people will treat her differently, often in ways that are harmful. A label can replace evidence which can only be obtained by real experience in getting acquainted with someone. Labels can obscure the great range of differences among people with special needs. There are people with special needs like Helen Keller, who lecture and teach. There are people with severe physical challenges who run large government agencies. On the other hand there are people with special needs who cannot communicate and have little understanding of the world. There are people with special needs who like classical music. There are others who love CB radios and stock car racing. The only thing that people with disabilities often have in common is that they do not have access to the normal experiences of daily life that most of us take for granted. If their special developmental needs are met they can join us in the mainstream of society.

Mainstream of Society: The broad range of normal activities and roles that people fill in daily life which are generally accepted and valued by society. A criminal is not in the mainstream of society; a person who works at a useful job usually is. Some of the normal activities that are considered to be in the mainstream of social life are work, school, community recreational activities, living in a neighborhood eating at restaurants, shopping at stores, and having friends. In the past, people with special developmental needs have often not been allowed to enter the mainstream of society.

While the labels which we give to people are often delusions, the special needs which people have are very real. When these needs are not met the suffering which ensues can be incredible. Parents of a child with severe mental retardation who cannot find an appropriate babysitter may almost never be able to go out to see friends or have a night out. When a young man with cerebral palsy cannot find a home in the community where an attendant

can help him to dress and eat, he may live his life on the ward of a hospital with hundreds of others who share his lack of opportunity. When a seeing-impaired child is not given books with large print, he may not learn to read. If a slow learning toddler is not given a good nursery school, she may never succeed at anything in school. The suffering caused mostly by ommission - by failing to do what needs to be done - is all too real.

Seven Kinds of Special Needs

If you are interested in helping a friend, relative, or neighbor who has special developmental needs, you have to understand the current ways that services are provided for him. There are two ways that parents and professionals in recent years have found to talk about who is in need of special assistance. One way is known as a noncategorical functional definition of who has special developmental needs. It tries to look at what kinds of help people need rather than what conditions these people have. This approach is currently the basis for the services provided by federal law, the Developmental Disabilities Assistance and Bill of Rights Act. This law identifies seven areas of life in which people may need special assistance. According to the law, anyone who needs substantial assistance in any three of these areas is eligible for services for people who are labeled developmentally disabled. Their need for special assistance must have arisen before age 22 and it must seem likely that they will have special needs all of their lives.

Noncategorical Functional Definition: A way of deciding who has special developmental needs by looking at the day-to-day kinds of special problems which people have because of physical or mental conditions, rather than using labels. For example, a person is defined as having a special developmental need if they have trouble with 3 basic areas of living such as communication, self-help, or work.

Developmental Disabilities Assistance and Bill of Rights Act: A landmark law which has made a substantial difference in the lives of many people with special developmental needs by requiring states that receive federal money to have a protection and advocacy system for people with special needs (PL 94-103, amended by PL 95-602).

Self-care. Some people need special assistance in caring for basic physical needs such as eating, toileting, dressing, and grooming. As infants, all people need extra assistance with these basic self-care skills. And most of us need some help with them during times of illness or convalescence. Self-care skills can be taught to people through careful, structured instruction. There are also many kinds of adaptive devices which can help people with special needs for self-care assistance. When people are not given a chance to learn self-care skills through good instruction, they often become more helpless and dependent than necessary. Help with self-care skills needs to be individualized. When people are fed and dressed en masse, they are often subjected to dehumanizing practices. Each of us has different tastes in food and clothing and slightly

different ways of eating and washing. If people do not get quality individualized assistance with self-care they may have trouble thriving which can result in poor mental and physical health and early death.

Mobility. Getting around is a part of life most of us take for granted. We move from room to room, from sitting to standing. But when a person has a physical challenge such as paralysis of a limb, she takes none of this for granted. A chance to move where she pleases may be central to her life. The need for special assistance with mobility goes beyond learning to move arms and legs or to operate a wheelchair. It includes the opportunity to learn to use public transportation. And it includes the chance to actually enter buildings and rooms which have been modified so that wheelchairs and walkers can fit. Recent teaching methods and mechanical devices have opened up a whole new world of possibilities for people who previously have been severely confined. Imagine the pain and frustration of not being able to move about as you please.

Physical Challenge: An extra difficulty which a person must face such as requiring wheelchairs to move, hearing aids or sign language to communicate, and special aids to see. People with special developmental needs often face physical challenges their whole lives.

Receptive and Expressive Language. The ability to communicate lets us enter the world of other human beings. It allows us to ask for help, to order a coke, to express our feelings, to listen to the lyrics of a favorite song. A person who has difficulty receiving or expressing language, is cut off from the enrichment of normal communication. Needs for help with communication can take a thousand different forms. An infant who is hard of hearing will need special training to use what hearing she has. A young man with a stutter may benefit from speech therapy. A person with difficulty remembering words may learn to communicate by pointing to pictures. Others may benefit by learning to use their hands to make signs or to read lips. There are many kinds of help which can allow a person to be much more independent as a result of increased communication skills. Without this help, however, people can be cut off from human contact which most of us take for granted.

Learning. If a school child needs more help than is normally offered in a regular classroom, he may qualify for special education services. Special assistance in school can take many forms, from different books or instructional materials to separate classrooms with specially trained teachers.

Federal and state laws require that all children receive a free and appropriate education. It also requires that children receive an education in the least restrictive environment. The concept of the least restrictive environment is for children with special needs to have as normal a school experience as possible without sacrificing their educational needs. One example of providing education in the least restrictive setting is having an aide give a child special assistance in the regular classroom. Learning does not just happen during the school years. In fact, most of us engage in some form of education after age 22, either for our work or leisure purposes. Many adults with special needs continue to need and desire educational experience. They can benefit from adult education.

Self-Direction. If a person usually needs assistance in deciding where to go, who to see, and how to spend money, their needs are included in this category of self-direction. At one time or another all of us have some trouble making decisions about how to use our time or money, or how to best take care of our own interests. We may seek advice from friends, teachers or relatives. Or we may talk with a professional counselor in order to get advice. Some people need this kind of help almost every day. Others may only need extra help to handle one area of their lives, such as budgeting or shopping. They may need a guardian to help them with money or housing matters. If a person does not get necessary assistance with self-direction he can be exposed to danger, abuse, or ill health. Too much or the wrong kind of assistance with self-direction can be hazardous by increasing a person's helplessness.

Economic Self-Sufficiency. If you have ever bee laid off work or had to spend a long time hunting for a job, you know what it can be like to have difficulty being economically self-sufficient. About two million young people have physical or mental conditions which make it very hard for them to earn a decent living without special work programs or training. The kind of special needs they have can vary from on-the-job training to special mechanical devices. For example, braille measuring

Least Restrictive Environment: The setting for a person to receive educational services must be in as normal an environment as possible, according to law. The least restrictive environment in special education means services which meet the persons's needs and provice an appropriate education and at the same time allow him the most contact possible with non-handicapped persons. The opposite of the least restrictive environment can be segregation, isolation, and placement away from normal life.

On the Job Training: People get trained while working at a job instead of going to school to learn to do it. On the job training can be arranged by the Department of Rehabilitation. The Department and an employer agree to train perople at a job and to give them the job once they are trained. On the job training has proven a successful way to allow people with very severe special needs to do real work and earn a living.

tools can assist a worker to do intricate machine tooling. We know for a fact that most people with special developmental needs could work and earn a good portion of their income if their special needs were met. Sadly, about 60% of people with special developmental needs are unemployed and the other 40% earn very low wages. These people with special work needs share a lot in common with many workers. As noted earlier, about one out of seven people who work will be laid off for six months or longer during their career because of an injury or illness. Many of us will need some special assistance to earn a living during our working lives. Citizens with special needs can work and they want to work. There is plenty of evidence that even the most severely handicapped people can earn a living if they are provided with the right kind of work setting.

Capacity For Independent Living. This is a broad area. It includes the many skills we need in order to live in our own home or apartment such as cooking, cleaning, shopping and scheduling. Some young people cannot reasonably be expected to live on their own without some special help because of physical or mental conditions which limit their skills. This help may take the form of extra supervision, as in the case of a supervised apartment, or it may mean extra training in independent living skills. A person may need a full time attendant in order to live independently or he may need extra mechanical help, such as lifts or special switches.

Of all the areas of special needs, the capacity for independent living is the one shared most by people with developmental disabilities and other citizens. The more services we have to allow persons with developmental disabilities to live independently, the more we should be able to benefit all citizens who need this help.

If you know of a friend or relative who has special needs in at least three of the seven areas just described, and if he manifested these needs before age 22, he is probably eligible for the many services available to persons who are said to be developmentally disabled.

Categorical Definitions Of Disability

Categorical Definition Of Disability: An emphasis on what is wrong with a person instead of what a person needs to participate in normal daily life. A ategorical definition looks at the conditions which people have such as autism, mental retardation, or cerebral palsy.

A second way to describe persons with special developmental needs is to describe the conditions which they have. This approach is known as a categorical definition of disability. This approach can be dangerous because it results in people being categorized in terms of labels and seems to promote stereotypic responses toward people. On the other hand, many programs and organizations focus on groups of people with similar disabilities. Whether the categorical nature of many organizations is a good idea or not, it is the current state of affairs. If you are concerned about a relative, friend, or neighbor who has special needs, then it would be useful for you to understand the categorical approach to disabilities as well as the noncategorical approach to disabilities which was just described.

Mental Retardation. The largest category of conditions which lead people to have special developmental needs is mental retardation. Three out of every 100 people have mental retardation. For the most part, it is a condition which involves learning more slowly than is normally expected.

Some people learn more slowly than others. All people learn different skills at different speeds. One person may quickly learn to shoot baskets while another may need to practice thousands of times. Some children learn to read quickly with little help while others need years of good instruction. Still others may need to be taught to read with special print or materials which break the task of reading down into small steps. A person who learns much more slowly than most people may need extra help in order to become as independent as possible. Most people need extra help to learn some things in their life. To learn computer programming most students would need special books, a good teacher, and a chance to practice on a computer. Similarly, people who are slow learners may need special materials, good teachers, and lots of practice at skills which are needed for independent living.

Skills which people need to live on their own are called adaptive behavior. People learn adaptive behaviors all through life. Infants learn to smile, stand, and reach for things. Toddlers learn to talk and follow directions. School age

children learn to pay attention, write, solve arithmetic problems, read, and make friends. Young adults learn to work, cook, and make decisions. Older adults learn to take care of a family, have hobbies, and join in the community. Some people learn adaptive behaviors more slowly than others. If a person is noticeably slower at learning adaptive behaviors, she may need special help in order to achieve the things that most people want--that is, to have friends, to work, to have fun, and to live in her own home. To get funding for this special help, a person who learns adaptive behaviors slowly usually has to be tested and usually is given a label.

Slow learners are tested with I.Q. tests and with adaptive behavior tests. I.Q. tests are often used to predict how a person will perform in school. There are many problems with I.Q. tests. They can be inaccurate; they measure only a small area of skills, and they tend to discriminate against people from different cultural backgrounds. Because of these problems, I.Q. tests are illegal in California schools for use in placing students in special education classes. However, they are often still used to decide if a person can get special help through the Regional Centers.

Regional Centers: The place to go to find services for people with special developmental needs. Regional Centers do evaluations and diagnoses and provide case management. They can provide out of home placements and are responsible for all placements in the state hospital system. A California State law, the Lanterman Act, created the regional center system.

It is important to understand that I.Q. tests give only a limited picture of a person and may say little that is accurate about her potential for learning. If a person scores 70 or below on a standard I.Q. test and is delayed in two areas of adaptive behavior, she is said to have mental retardation. About 3 out of every 100 children are called mentally retarded because they learn adaptive behaviors more slowly than most children. There are over 650,000 people with mental retardation in California. Most mentally retarded people look like everyone else and only have trouble learning fairly complicated skills in school. Some people with mental retardation, however, need a lot of extra help to learn skills which seem simple, such as dressing, eating, or shopping. Nevertheless, all people, regardless of how slowly they learn, can and do keep on learning.

Autism. Another handicapping condition which is not as common as mental retardation is autism. It is a disorder of learning; it is also a disorder of normal social development. It is usually evident

in infancy. Autistic children develop more slowly than normal children. They do not relate to their parents normally and may not respond to affection. Instead, they stay closed off in a world of their own sensations. Autistic children frequently show stereotypic behavior such as repeating movements over and over again. For example, they may rock back and forth or weave or flick their fingers repetitively before their eyes. Autistic children may learn well in some areas while they are delayed in others. A child might have very poor or strange speech but be able to put together complicated puzzles. People with autism sometimes display unusual behaviors such as tantruming or laughing inappropriately. Autistic children are often noncompliant and show frustration when demands are made of them. Until recently, autism was thought to be a hopeless condition. But in the past 15 years, educators and psychologists have found improved methods for teaching autistic children. These methods use lots of structure and skills are taught in small steps with clear cues and rewards for the students.

People with autism and their families may have many special needs. Since autism often appears in infancy, very early intervention along with parent counseling and instruction can be very helpful. In school, autistic children need very structured instruction. After the school years, people with autism may need special community living arrangements and work settings. Presently these special kinds of help are not available to autistic people in most communities.

Cerebral Palsy. People who have cerebral palsy have difficulty moving normally. This difficulty comes from damage to their nervous systems. Usually the damage happens before birth, right at birth, or in early infancy. Because of nerve damage, their muscles may be weak or floppy, or else they may tighten up and become rigid easily. Some people with cerebral palsy have trouble with balance since their muscles may move uncontrollably.

Some people with cerebral palsy learn very quickly, while others have a slower rate of learning. Often people with cerebral palsy are not able to speak clearly and may need extra help to communicate. There are people with cerebral palsy who have gone to law school and there are others who hold jobs in factories. Some have mental retardation and are forced to live in institutions because there are few other places which can give the kind of special help they need.

There are such differences among people who have cerebral palsy that their needs vary greatly. One person may need speech therapy and a special wheelchair to get around her college campus. Another may need training in self-help skills, a special living arrangement, and communication equipment. Most people with cerebral palsy will have special needs at each stage of life. If these needs are met they can live and work in their own community. If they are not met, they may be excluded from normal activities and forced to subsist on public support.

Sensory Deficits. Many people face the challenge which comes from partial or total loss of one of their senses - sight or hearing. Some people have more than one sensory deficit. Helen Keller is the most famous example of a woman who dealt with the dual challenges of being deaf and blind. Most people with sensory deficits have lost only part of their visual or auditory acuity. A person who is legally blind may need enlarged print in order to read. A person who is partially deaf may need a hearing aide in order to understand others. People with sensory challenges have a huge range of abilities. There are judges who are blind and there are very slow learners who are blind. As with other disabling conditions, sensory deficits can occur at any time of life. Many Americans will develop impairments in seeing and hearing. There are many kinds of special devices and assistance which allow people with sensory deficits to live more independently. For example, there are special wristwatches, braille micrometers, which enable persons who are blind to tell time. Deaf college graduates can now join the professions with the help of special education programs.

Convulsive Disorders And Other Neurological Handicaps. Epilepsy or convulsive disorder is a condition in which the electrical patterns of the brain and nervous system are disordered. There are many kinds of convulsive disorders. Mild forms simply cause a person to temporarily lose their concentration and attention span. Others can involve sudden, violent disruption of a person's functioning with unconsciousness and uncontrolled contractions of most of the muscles of the body.

There are many lesser forms of epilepsy between these extremes. About one person out of every 100 has a convulsive disorder, and most of them are able to live normal lives with the help of medication. Sometimes people with another handicapping condition also have epilepsy. Medical doctors can tell for certain if a person has epilepsy or another convulsive disorder by taking a complete personal history and administering an EEG (a test of the electrical patterns of the brain); or by observing a seizure. People with seizures often face the same kind of attitudes which plague other Americans with special needs. There are people in all walks of life, contributing everyday to society, who happen to be challenged by convulsive disorders.

There are many other medical conditions which can impose challenges and hardships upon young people. You have probably heard of some of them such as multiple sclerosis. A young person who has any medical condition which causes significant difficulty in daily living is probably eligible for the services available to people who are said to be developmentally disabled.

Multiple Sclerosis: A disease which affects the nervous and muscular systems. It is a progressive disease, which means that the person's condition probably will get worse over time. M.S. usually strikes young adults. People with M.S. often feel very weak and lose control of many parts of their bodies. They usually must use a wheelchair. No cure is yet known for M.S.

Causes And Prevention

Many disabling conditions can be prevented. Prevention is probably the single most efficient and potent way of reducing the number of persons who have developmental disabilities. Presently few public resources go toward prevention. Our shortsightedness in this regard costs us all dearly.

A review of the causes of developmental disabilities indicates how this problem is tied to many other problems of our society. If we work on prevention we will attack problems which affect all of us -- poverty, public health care, and family planning. One half of all developmental disabilities could be prevented if we fully used the knowledge that we now have. Perhaps one day these conditions which challenge people lifelong will almost vanish, just as the plague which used to be the scourge of civilization is now almost nonexistent. For such progress to occur we will all have to understand more about how to bear and raise healthy children in a wholesome environment.

Many developmental disabilities exist due to conditions that began before birth. These causes involve several known chemical and biological factors. Sometimes parents carry genes, the building blocks of new life, which lead to birth defects. Genetic counseling based on medical science, can help parents who suspect that they may carry genes which can lead to birth defects. It is also possible for doctors to test the genetic make-up of a fetus to see if it will be healthy. Some kinds of physical conditions can injure an infant in the womb, but good medical care during pregnancy can often lead to the detection and prevention of these conditions.

An infant can be damaged during pregnancy by poisoning with chemicals, including alcohol or cigarettes consumed by a pregnant woman which can limit the growth of a fetus. Also, infections during pregnancy can pass from mother to child. One of the most damaging is rubella - German measles - which can leave a fetus deaf and blind if it occurs in the first three months of life. A lack of good food can also place an unborn child at risk and it is now widely accepted that proper nutrition during pregnancy is essential.

One of the simplest ways to reduce the number of infants born with birth defects is family planning. Some times of life are better than others for bearing children. Teenage mothers are much more likely to give birth to children with handicapping conditions than are older mothers. This is partly because many teenage young women are not completely ready physically to bear a healthy child, and partly because many teenage mothers do not have the stable home life and careful medical and nutritional help needed to have a healthy baby. In a few high schools in the U.S., professionals and parents have started family planning clinics. They have also started parenting classes to teach teenagers what is needed to raise a healthy child. These programs have been very successful in cutting down on teenage pregnancies and problem births.

Once children are born, they need to live in a setting with a certain amount of order, space, affection, and good food. When children are raised in harsh conditions of overcrowding and despair, they sometimes do not develop normally. The main cause of mild mental retardation is poverty. When these children are given proper nutrition and enriched education in early childhood, they often do as well or better than children from more fortunate homes.

Biological Factors: Causes of handicaping conditions from within a person's body that can affect their normal growth and development.

Genetic Counseling: Before a couple decides to have a baby, they can talk to a doctor or scientist who knows a lot about genes. They can learn whether they stand a high risk of having a baby with inherited illnesses or handicapping conditions. If the woman is pregnant, the doctor may prescribe tests to see if the fetus has healthy genes. Genetic counseling is especially important for people who suspect that they may have generic problems.

Rubella: A type of measles. If a woman catches rubella early in her pregnancy, the baby is likely to be born deaf and blind.

Family Planning: A process of thinking and talking about when a couple wants to have children and deciding how many children to have. Family planning means using practices or contraceptive devices to insure that children

The problems of people with special needs cannot be separated from the major problems which face our society - poverty, unemployment, and racism.

Thousands of children become disabled each year from accidents. The single greatest cause of lasting injury to children is the automobile. When a car that is moving 30 miles an hour collides with something, a child can be thrown through the windshield with the same force as if he were dropped from a three story building. The consistent use of seatbelts and car seats for children could prevent 90% of the deaths and almost 80% of the serious injuries inflicted on children each year. Some organizations for people with special needs have sponsored community education programs to encourage the use of seatbelts and car seats and some community organizations actually loan car seats.

Many causes of developmental disabilities are completely unknown. There is great need for more research into the causes of delayed development and birth defects. This kind of basic research is likely to have spin-offs which will benefit millions of citizens.

If you have a friend, relative, or neighbor who has a special developmental need, perhaps you are interested in helping out. In order to help, you need to know something about the services that are now available and how you can get involved. Moreover, since many of the services for persons with disabilities are limited or of poor quality, you may want to learn how to advocate to improve these services.

are wanted and planned. Family planning clinics offer information and counseling. Planned Parenthood is one of the largest family planning organizations.

JEFF AND NORMA

When Jeff and Norma married, Norma's mother insisted that Jeff have an operation to make him sterile. She believed that Jeff and Norma would not be able to safely raise children. A client's rights advocate agreed that the operation would be the best thing but was concerned that Jeff understand clearly the purpose of the sterilization. The staff of the workshop and Norma's mother had several long talks with Jeff about the sterilization. He got headaches after the talks. No one was sure that Jeff understood because his answers to their questions were often unclear. Jeff's friends thought he was more concerned with pleasing them by giving the right answer than in understanding what it meant to have the operation. Finally, Jeff's mother-in-law took him to the doctor and the surgery was performed. Technically, the doctor was breaking the law in because the surgery was not approved by a special state board on sterilization of people with developmental disabilities. In fact, surgery without the board's permission is commonplace and is usually arranged by parents who are concerned about their children's potential troubles in parenting children.

Jeff and Norma like to travel. They go on bus trips almost monthly to visit friends around the state. They particularly like to go to flea markets. Jeff collects old TV Guide magazines and Norma likes to shop for kitchen items.

The people who know Jeff and Norma well agree that they have a pretty good life. They all speak of the couple fondly and enjoy being their friends.

Chapter II, HUMAN SERVICES ARE AVAILABLE FOR PEOPLE WITH SPECIAL DEVELOPEMNTAL NEEDS

Millions of Americans have special developmental needs. By definition, a need is a basic requirement for a decent life. If a need is not met, a person suffers. Meeting a need in an inadequate or dehumanizing way, can contribute to a person's difficulties. Human services must not only take care of the needs of persons with developmental disabilities, but they must do so in ways which enhance the quality of their lives.

Individualization

A consensus is emerging among parents and professionals that good human services are organized around three ideals: individualization, normalization, and the developmental model. Individualization simply means that services are personalized. There is a match between what a person needs and what he receives. There is a match between the ways that a person learns and how teaching is delivered. Also, there is a match between a person's personal preferences and the way a service is delivered.

Take, for example, a young man who wants to leave his parent's home to live on his own. Because he is a slow learner he does not know how to cook for himself. He would like to live in his own apartment but his parents are concerned that he may not be able to take care of himself without extra assistance. A good human service for this young person would first find out what he needs to learn to live in the apartment. It might assist him to move into an apartment. A home skills trainer might help out as a homemaker for a few hours a day and teach the young man how to cook. The trainer would first find out what he needs to learn and what kinds of food he prefers. As the young man becomes more competent at cooking, the services of the trainer would no longer be required and he would gradually fade out of the picture. This service model provides the person with the appropriate intensity of service in the most desirable setting. It would take into account the wishes of the parents and the client. The young man would not be required to always cook a set menu or to

Individualization: The idea that services for people should be centered around individual needs, preferences, and outlook. Individualized services treat each person as unique and show regard for their needs and feelings. Individualized services are needed to fit an individual, rather than modling an individual to fit existing services.

Developmental Model: The idea that anybody can grow and learn at any stage of life. The developmental model is dynamic and includes the notion that one skill builds upon another. It implies that merely making a person comfortable is not enough; they should always be given the chance to learn new skills and have new experiences.

first graduate from a training program before going into the apartment. The training sequence would be individualized. Both the menu and the apartment would be personalized.

The opposite of a personalized living training program might be seen in a state hospital. In the hospital, the same young man would not be able to develop independent living skills. He would not be able to learn to cook as cooking is done on a mass scale in the hospital kitchens. He would not be able to personalize his living space because decorations and furnishings are purchased by the state on a mass scale. The group care system and facilities of our large hospitals provides the clearest example of the opposite of individualization.

Normalization

A quality human service system would also provide normalized services. Normalization is a powerful, if often misunderstood, idea imported from Scandinavia about 20 years ago. Its originator was head of services for persons with mental retardation in Norway. He began thinking about the differences between his own daily life and the kind of daily life available to people living in his country's hospitals for the mentally retarded. He noticed that people did not have normal schedules of rest and work. They did not have normal choices of food, friendship, and leisure activities. And they were not getting taught to behave in ways which would ever let them fit back into normal society. So he began spreading the revolutionary idea that human services should promote ways of living and learning that are part of the mainstream of society. The opposite of being a part of the mainstream of society is being deviant. A person who is considered deviant is usually excluded from society like criminals or mental patient. They are treated with pity, like a charity recipient; scorn, like the young outcasts on any school playground; or fear, as was so often was the case with persons with mental retardation who were put away in hospitals to protect society. On the other hand, a person who is accepted in the mainstream of society may live in your neighborhood, get up and go to work

in the morning, eat in a restaurant, and go to church on Sunday. She might need extra help to do these things, and the help would be provided in ways which do not mark a person as deviant. If she goes to church she might go with a small group of family or friends, but not on a special bus with 20 other people who are said to be retarded. She would not sit in a special section of the church, nor would the church members give her candy as if she were a child.

In a pluralistic society, the mainstream of life offers a wide choice of roles. A person who is labeled deviant has few choices. He is always treated with pity or scorn. He always rides the same special bus with the same group of residents. And he almost always acts as others expect of him. But a person who is allowed to fit in can have a whole world of choices. He can live in a group home or a supervised apartment or a special mobile home. He can dress in comfortable clothes at home and more formal clothes at church. He can play pinball one day and watch a movie on another. The mainstream, for most people, offers the widest range of positive choices. So if we are creating homes and lessons and support services for people, we should do so in ways that let people belong to the normal world of choices.

Developmental Model

A final principle of good human services is that they include attention to the developmental model. This model embraces the idea that anyone can learn, regardless of their stage of development or age. Even a person with the most severe mental or physical challenge can take another step. An infant who is delayed can learn to raise her head. A slow learner can learn to write checks at the bank. A person who is blind can learn to walk around the city. The developmental model assumes that no one is stuck. The opposite of developmental services is static care, which says that a person will always be the way she is. Therefore, the best we can do is keep her comfortable and clean. In schools where teachers do not believe in the developmental model, they often

become babysitters. Instead of teaching the children new skills, they entertain and comfort the children.

The developmental model implies habilitation. Habilitation is the use of the best teaching methods and services to allow a person to become as independent as possible. An adult learning center which believes in habilitation teaches adults to use tools and to cross streets. A center which does not believe in the developmental model lets the clients color in coloring books although they are 40 years old. The developmental model, normalization, and individualization are powerful ideas which must begin to shape the kinds of services we create for our fellow citizens with special developmental needs.

Habilitation: The process of helping a person become more independent and productive by teaching skills and providing services which lead to independence.

The Way It Is Versus The Way It Should Be

In present day California, our services for persons with special developmental needs usually do not follow the principles of normalization, individualization, and the developmental model. Most of our resources are aimed at placing people in exclusionary settings such as state hospitals or special schools. Most of our money assists in taking people away from their natural families rather than helping keep those families intact. Most of the work we have for people with special needs is trivial and minimally rewarding. In short, there is a lot of work to be done to create good human services for people with special needs.

Home Support. People with special developmental needs have families like everyone else, but often great stress is placed upon the family by the constant requirements of caring for a loved one with a handicapping condition. A child who is a slow learner may behave in strange or difficult ways which cause parents lots of stress. Or a child with special needs may require extra physical care - special diets and medications, special equipment and consultations. All of these special needs take time and reserves of energy and money. Right now there are few services available for families with children who have special needs. Most of our resources and money goes to support children and adults in foster home arrangements - called

community care homes in California. But no matter how committed a foster parent might be, he is not likely to have the love and vested interest of a child's real parent. In the long run. the best advocate and lifelong friend a person with special needs is likely to have is a parent, sibling, or close relative. If the family bond is broken by placing a child out of his own home, a great supportive and protective resource is lost. There are a variety of services which could help parents keep their children at home during their school age years. Placement out of home could become much more a matter of natural development as a child reaches adulthood. Some of these services are now available around the state. Others need to be started. There is still not a complete, coordinated set of services for developmentally disabled children at home.

SSI. Supplemental Security Income is an income transfer program. Through the social security system, monthly payments are made to families with children who have a condition which makes it unlikely that the child will ever be fully independent. Parents or guardians can apply directly for SSI payments at any local social security office. There are some serious problems with the SSI system. One of the most serious is that people can lose their eligibility for SSI if they begin earning enough money to support themselves. They also lose the Medicare aid that usually comes along with the SSI. The inflexible guidelines for discontinuing SSI and Medicare benefits now serve as a disincentive to work for many people.

Respite Care. Respite care services allow parents to have some time away from their child with special needs. The time away might be an evening at the movies or it might be a week-long vacation. Respite care can be provided in the home by having a trained caretaker come and watch the child. It can be provided out of the home in a trained careprovider's home. Respite care services are inadequately supported and do not even exist in most communities in the State of California at present. Most parents have to rely on relatives or the luck of finding a good babysitter. More often than not, they find no one at all who can adequately care for their child with special needs.

Medicare Benefits: Payment for part or all of a person's medical expenses by the federal government. Citizens who have special needs which prevent them from independent living may receive monthly support checks from the federal government. They are also eligible for Medicare benefits to help them pay for medical costs.

Crisis Services. Crisis services are designed to relieve parents for at least 24 hours if there is a serious illness in the family or any emergency situation. These services are now very rare.

Case Management. Quality case management centers around a client's individual program plan. The case manager is responsible for implementing, monitoring, and evaluating the appropriateness of an individual plan. Case management is usually provided by a trained social worker. It involves coordinating the services which a person with special needs requires. Case management includes regular reviews of a client's developmental needs. Currently, case management is offered by the Regional Center System in California. Case managers, usually social workers, monitor the care and needs of Regional Center clients.

Homemaker Chore Service. Homemaker services offers the help of a person with homemaking skills to take full or partial responsibility for the household chores in a home where a resident has special needs. Some homemakers can also provide training in these household chores.

Home Nursing Service. This service provides medical care to a person in their own home and can avoid placement in a hospital or nursing home. Home nurses also provide training to parents and care providers in areas of specialized care for some persons with special developmental needs.

In-Home Training. A qualified instructor gives training at home for parents, consumers or service providers. Training is related to the person's individualized needs. The instructor trains parents or careproviders in how to develop goals, teach skills, and control inappropriate behavior.

Trained Day Care. Trained day care involves the provision of appropriate care, stimulation, and teaching to young children in either a day care center or at home. Day care programs allow the parents of children with special needs to work and can be publicly or privately operated.

Behavior Management Intervention. A qualified psychologist, social worker or special educator helps a family to define a difficult behavior, design a plan to remediate it, and monitors the program. Training of parents and care providers is also offered.

Keeping People At Home

The support services, which have been briefly described, can allow many more children and young adults to stay in their natural homes rather than being placed in foster care or institutional care. Some parents might need only one service occasionaly. Others might need all the services. For most people, their natural home allows them the best chance for growth and loving care. Only in unusual cases are children better off in a careprovider's home. Presently, only about 3% of our resources which are spent for people with special developmental needs go to in-home services. A reordering of our priorities could improve the quality of services to many people in California.

Expanding Normal Opportunities First

The idea of first supporting parents in their efforts to care for their children with special needs is part of the theory of normalization. This theory leads us to the idea that the first place to turn for services for people with special needs is to community services which already exist. When looking at ways to improve services the first question becomes "How can we expand the services which already exist for most citizens in order to make them available for people with special needs?" Most children are able to grow up in their parent's home. We have just looked at a few of the kinds of services which could enable the family to be a stronger resource for children with special needs. This same line of thinking can be applied to all the areas where human services are needed. For example, in the field of health care, we would look at how to expand the services now available to most citizens to include those who have special needs. The training of general practitioners could be enlarged to include courses

on developmental disabilities. The physical therapy clinics of neighborhood hospitals could be expanded to serve persons with cerebral palsy. This expansion of normal services is likely to cost less than creating separate programs with their new layers of administration. School boards should investigate the remodelling of existing neighborhood schools to accommodate students with special physical needs rather than plan to build a new, segregated facility. Government could establish incentives for normal businesses to hire and train persons with special needs rather than creating new segregated workshops.

Transportation is another area in which existing services should be expanded to better serve the needs of people with developmental disabilities. Some cities, such as Atlanta, Georgia, have developed ideal transportation programs. New buses are purchased with lifts and wide doors so that all citizens may ride. Bus drivers are trained to give the extra assistance required by some passengers. As a result, a normal public service now includes the whole community. People who learn quickly and those who learn more slowly, people who walk and those who use wheelchairs, can all ride together on their way to town and back. Making normal services accessible to all citizens is almost always preferable to creating new, separate services for persons with special needs.

Public School Services

By federal mandate, all children have the right to a free appropriate public education. It may come as a surprise to learn that such a law was even needed. But as recently as 1975, as many as two million children were completely excluded from public school services because they had special needs. Even today, with the federal mandate, there are far too many excluded children. If a child is excluded from normal society in school, she is likely to be excluded as an adult. The federal law which entitles all children to a public education is P.L. 94-142. It is backed up in California by parallel state law. Along with guaranteeing a public education, it mandates that school services be provided in the least restrictive environment and still meet a child's educational needs.

Least Restrictive Environment. Some settings are more restrictive of opportunity and freedom than others. A prison is more restrictive than a hotel. A hospital has more limited choices available than most normal homes. The intent of the congressmen and senators who passed P.L. 94-142 was to see that children with special needs be educated with as much contact as possible with non-handicapped children. They believed that a classroom made up only of children with special needs is likely to be more restrictive than a mixed classroom. A segregated school which serves only children with severe needs is not as likely to provide as normalized an educational experience as a neighborhood school which includes children with special needs. Educators and parents have the difficult job of balancing two ideas: least restrictive environment and most appropriate education. The least restrictive environment is a school setting most like that of normal children in the community. An appropriate education is one in which the content and teaching methods match the needs and learning style of the student. Sometimes there are compromises which must be made between the least restrictive setting for a child and the most appropriate education. Sadly, the deciding factor often is not what is best for the child but what choices now exist. California has a large and expensive legacy of segregated schools for children with special needs. Usually children are sent to these schools by default because no other community alternatives exist. The state hospitals and segregated schools in California make up an enormously expensive segregated system of serving people with special needs.

The Criteria Of Ultimate Functioning. Another aspect of normalization, individualization, and the developmental model is known by the formidable name of "the criteria of ultimate functioning". It is really a common sense idea that if you want a child to become an independent, productive adult you must educate him in a way that will prepare him for work and independent living. Any educational setting or experience can be examined in the light of this question. If we want children with special needs to grow up to be productive citizens, then our education must include preparation for this role, from early childhood through adulthood.

For the most part, we apply the criteria of ultimate functioning to education of nonhandicapped children. Few parents would accept having their child taught only to listen to stories and to sing songs. When the criteria of ultimating functioning is applied to the education of children with special needs, they are taught how to work, travel about the community, shop, cook, and enjoy recreation. They are taught behaviors that are generally acceptable in the community. When the criteria of ultimate functioning is not applied, children end up as dependent adults, with little experience of normal social life. They do not know how to work or care for themselves. They end up as candidates for outmoded adult services. So an outmoded educational service provides fodder for an outmoded adult system. Advocates for persons with special needs face the challenge of changing this complex, intertwined system.

What We Need From Public School Services For Children With Special Needs

There are some school systems in the United States which do provide quality services for all children in the least restrictive environment. They serve as good models for what we would develop in California. For example, the Madison, Wisconsin, school system has for years been teaching children with special needs to ride the bus, work at jobs in the community, go to the movies, swim, and shop. As part of their school program, the educators in Madison study what happens to their high school graduates in order to see if their education has prepared them for productive lives in the community.

The school system in Tacoma, Washington, has been integrating all children in neighborhood schools for almost 20 years. Even children with very great special needs go to integrated schools in town and spend part of their school day with non-handicapped children. Programs which follow the ideas of normalization, individualization, and the developmental model are working in other places.

Accessibility. Most neighborhood schools need to be remodeled or rebuilt so that all children could use the same bathrooms, gymnasiums, lunchrooms, and libraries. Right now our school buildings speak a powerful language of exclusion for physically challenged youngsters.

Integration. Quality education is best delivered in integrated settings. When a whole school is set aside for children with special needs they lose out on the many kinds of peer modeling and social learning which can benefit all children.

Structured Interaction with Nonhandicapped Children. Physical integration of children with special needs is not enough to assure that they will have a positive experience of nonhandicapped children. The teachers and administrators in a school need to help structure the contacts between the children so that the similarities of all children are emphasized. When children are given assistance from adults to appreciate others' differences, all can benefit.

Administrative Support. When a school principal supports programs for children with special needs, chances for success are greatly increased. Principals and administrators are key people in any effort to improve our educational system.

Individualized Instruction. Quality education for all children involves first finding out what a child needs to learn. Merely placing a child in a standard group and dishing out the same instruction to the whole group can be wasteful for everyone. Goals need to be written based upon the assessment of the child's needs. Parents or careproviders must be consulted in deciding what objectives should be taught. Then lessons are developed to meet the child's needs and style of learning. The child's progress needs to be monitored regularly so that each step of instruction is based on a solid foundation of previously mastered steps. Otherwise a child can miss the first part of a task and then not understand all the subsequent steps. Also, the teacher needs an on-going way to monitor how well a child is doing so that lesson plans can be changed accordingly.

Individualized instruction is one of the best examples of how the whole community could benefit from services which are now offered just to some children with special needs. Many special educators who have been recently trained understand how to individualize instruction. Their knowledge could be very useful to regular educators in personalizing instruction to all children. If special education were to be seen as an extension of regular education, rather than a separate specialty, many useful ideas could be exchanged to the benefit of all children.

Vocational Education and Independent Living Training. The criteria of ultimate functioning leads to the conclusion that schools must teach children with special needs practical skills which they can use to be productive adults in the community. Many children with special needs do not learn home-living skills, shopping, social skills, and work skills by just

watching adults. Instead, they need experience and good instruction.

Support Services

Children with special needs can benefit from a variety of support services in school. These services can be provided directly in private sessions with a child, or indirectly through consultation with classroom teachers.

Physical Therapy. Many children with special needs can benefit from instruction in strengthening and controlling their muscles. Children who use wheelchairs can better learn to turn and transfer. Children who use walkers can better learn to go up steps. Young people with physical challenges may need to learn better control of their hands and fingers. A trained physical therapist can give instruction in these areas or help a teacher to give the instruction.

Occupational Therapy. Occupational therapists can give instruction to children or their teachers in a number of important areas. These areas include such daily living skills as dressing, feeding and working with the hands.

Speech and Language Therapy. Limited communication skills are one of the most common difficulties of children with special needs. Trained speech and language personnel can help a child to communicate better. There are many kinds of therapy for many different kinds of problems. A skilled language therapist can be a great benefit to an educational program.

Special Recreation Instruction. Special recreation instruction can open a whole world of leisure skills and exercise to children with special needs. The instruction may be as simple as teaching a young person how to use a combination lock on a gym locker. It may be as complicated as teaching a child the rules of a team game through step-by-step practice in slow motion. Special recreation could be an extension of normal recreation training if regular gym teachers were given the training.

School Nurse Services. Many young people with special needs require some medical attention at school. A school nurse who is trained to work with these health conditions can meet their needs.

Consultant Teachers and Aides. Many special needs can be met in the regular classroom if the regular class teacher is given additional support. A consultant teacher can assist the regular class teacher in individualizing instruction for children with special needs. Extra aides can assist the regular teacher in implementing the instruction.

Resource Rooms and Resource Specialists. A resource room is a special education setting where a student goes for part of the day for remedial instruction. The resource specialist is a special education teacher trained in remedial instruction. He can assess the student's needs, write objectives, plan lessons to implement the objectives, and monitor the student's progress. Resource rooms enable students to participate more fully in their own regular classroom activities.

Specialized Classrooms. Some educators believe that many students are better served in special classes with other children who have special needs. Special class placement is controversial, but generally practiced in California and most states. A special class should be centered around the educational needs of the student. Many parents and educators argue that special class placement violates the least restrictive environment clause of the federal law. Others argue that many children with special needs cannot be given an appropriate education in the regular classroom and can benefit most from special class placement, at least for a while.

Vocational Programs

Citizens with special needs can and want to work. Pilot projects around the country have demonstrated that even people with very great special needs can learn to work. Not only is work one of the most valued activities of our society, but it allows citizens to contribute their energy and individuality to the common good. People who work participate in the common rhythm of life. Economists know that every dollar spent on vocational training programs for people with special needs is eventually paid back to society several times over in the productivity and taxes generated by the worker.

What We Have Versus What We Need

A few model programs around California and around the country have demonstrated the possibilities for quality vocational programming for people with special needs. As with other services, most current vocational programs fall far short of this demonstrated potential. As with other services, too little training of personnel and too few resources are allocated to this important area of human services. Most people with special needs are unemployed or underemployed. If they work, it is usually in a sheltered workshop. Although the quality of workshops vary, most only allow their clients to earn less than minimum wage doing trivial work. Restrictive SSI and Medicare rules serve as a disincentive to work. There is little progression to more challenging jobs and a general lack of habilitative training. Perhaps most damaging is that our present service system emphasizes segregated work settings for persons with special needs. Other countries have found ways to develop regular jobs for persons with special needs; they have also developed programs in regular factories where persons with special needs produce alongside fellow workers. Our present vocational system usually excludes people with severe handicapping conditions. We know that people with severe handicaps can produce complex computer parts and kidney dialysis machine parts. But the kinds of vocational training needed to let these people work in meaningful ways are generally not available. As a result, most persons with severely handicapping conditions either stay at home as adults or go to adult-activity centers where they do not do productive work.

Vocational Services for People With Special Needs - Kinds of Programming

Vocational and Prevocational Training. If children are going to be productive adults, they need to learn work skills as part of their education. Prevocational training can take many forms. Some schools have simulated workshops. Some innovative schools have developed on-the-job training (work study programs) for students to acquire practical vocational experience. Other model programs begin teaching work skills to children with special needs when they are in the primary grades. Vocational education can also be offered through regular class instruction.

Vocational Rehabilitation Counseling. Vocational rehabilitation counseling is offered through the State Department of Vocational Rehabilitation. The services are mandated by federal law which says that rehabilitation programming must be individualized. Rehabilitation counselors are trained in case management, assessment of client's needs, placement of clients in worksettings, and ongoing monitoring of their progress.

On-the-Job Training. Some of the most innovative programs for people with special vocational needs involve on-the-job training at regular competitive jobs. Job trainers are skilled at studying regular jobs and then teaching them to a person with special needs. Some model programs develop special equipment to allow people with physical challenges to perform the work. In another kind of on-the-job training, the employer directly gives the training to a vocational rehabilitation client.

Adult Education. California's extensive junior college system holds great potential for providing vocational training to persons with special developmental needs. This system presently teaches a wide range of work skills to nonhandicapped students. Some junior colleges have extended their programming to serve people with special needs. Some provide instructors to sheltered workshops and activity centers. Others have training programs on campus.

Sheltered Workshops. Sheltered workshops are presently the backbone of the vocational system for persons with special needs. Workshops can obtain a waiver from the Department of Labor in order to pay people at less than the minimum wage if their productivity is lower than that of competitive workers. This special variance allows the workshops to contract for many kinds of work. Some workshops are able to provide enough training and special equipment so that workers can earn a minimum wage or more. Sheltered workshops have many of the same problems as other components of the service system - underpaid staff, high staff turnover, too little staff training, and too few work contracts. Sheltered workshops are growing in size and number. As they expand, hopefully they will be able to develop more meaningful habilitative goals for their clients.

Work Activity Centers. Work activity centers are a fairly new part of the vocational service system. They are primarily meant to serve people with severe handicapping conditions. They teach adult recreation and craft activities and independent living skills as well as provide some work experience.

Public Works Teams. A few innovative programs utilize workers with special needs to perform needed public works jobs. In Los Angeles County, public works teams improve parks, roads and bridges. In a few national forests in California, people with special needs perform valuable conservation work.

Living Arrangements for People with Special Developmental Needs

Many people with special developmental needs require specialized living arrangements so they can live as independently and normally as possible. One of the most important aspects of a quality residential service system is support of families with children who have special needs, so that the entire family can live together until the child has matured. There are several kinds of out-of-home placements in California for people with special needs. Out-of-home placement is less preferred for children because it can break the protective family ties and eliminate many family resources normally available to children.

Supervised Apartments. As many as 10,000 people with special needs live in apartments in California. Some of these apartment arrangements offer supervision and training of residents. In a quality program, enough training and supervision is provided to insure that living standards are adequate and that the person is learning new skills in order to increase her independence and quality of life.

Independent Living Programs. Some communities have training homes where young people can learn the skills needed to live with more independence. An independent living program can teach many different skills from cooking to doing laundry to budgeting. Quality programs individualize their training and let people live in as personal a setting as possible.

Group Homes. Small group homes provide a living arrangement for up to 15 people. Homes vary from those which offer training and ongoing leisure and work activities, to those which only meet the client's minimal needs. The best group homes offer structured activities, individualized instruction, intensive programming and personalized living space. Group homes represent a national trend in residential arrangements for people with special needs. Quality standards

need to be established for homes, and resources allocated, so that quality can be maintained. Presently, care providers are underpaid and undertrained. Day to day, monitoring of quality of life in the homes is lacking. Meaningful habilitative goals for clients are also usually lacking. Group homes offer the promise of a positive life in the community for people who often have been excluded. Much work needs to be done to see this promise fulfilled.

Large Board and Care Homes. California has many large scale homes for people with special needs. They can serve up to 30 clients. Again, programming can range from nonexistant to excellent. More often than not, little real programming is conducted. Many advocates for community life for people with special needs believe that large facilities are inherently stigmatizing and depersonalized. Regardless of size, a quality living arrangement must provide individualized programming, personalized space, a regular schedule of activities and an atmosphere of respect and affection for the residents.

Small Institutions. Over 1,000 people with special needs in California live in facilities for 100 or more people in the community. The quality of life for people in these settings can vary greatly depending upon the quality of the management and staff. It is very difficult to provide a normalized daily life for people in such large, segregated groupings.

State Hospitals. Almost 9,000 Californians live in state hospitals for developmentally disabled persons. Many parents of persons with disabilities prefer hospital services because they believe that hospitals are more stable, safe living arrangements. The hospitals predominantly serve persons who are labeled severely and profoundly handicapped. However, numerous quality programs are beginning to prove the value of quality community alternatives to hospitalization for this group of individuals. The referral agencies listed in Chapter IV can tell you where these programs are located.

Community Care Homes. Most out-of-home placements in California are made to community care homes. These are family homes where the homemakers decide to have a person with special needs live in their home. Care providers can have

up to six residents live with them. The quality of care homes varies tremendously. In general, however, careproviders lack adequate funding, training, and support services. As a result, the majority of care homes provide little more than custodial care for their residents. A few model homes do offer on-going training and personalized living. Community care homes are becoming the dominant model for out-of-home services in California. Better training, financial and social support of careproviders could greatly improve this system.

The Benefits of a Comprehensive Community System

We would all benefit from a complete, quality service system for persons with special needs. These services would allow many more Americans to work and to contribute to their neighborhoods. Community-based services would offer valuable aides to many citizens. For example, some group homes now make the first aid skills of their staff available to the neighborhood. Neighbors can call the group home for help. Independent living programs for people with special needs could provide services for elderly Americans and temporarily disabled citizens. Resources and tax money which are channeled locally can provide significant benefits to a person's home community.

Society is enriched by diversity. The more we share daily life with all kinds of people, the more we are likely to expand our acceptance of all kinds of people. The more we provide for a quality life for our most needy citizens, the better off all the rest of us will be. One day, each of us will need some special help. If we have created communities which offer such help to people with special needs, it will be there for us when we need it.

JAMES

James is a young man with a dream. He wants to udy law. Right now he is frustrated in his daily b in a sheltered workshop. He sits in his wheel- air for eight hours each day and assembles small rts for agricultural equipment. He makes $3.00 hour. If he made any more money he would lose e medical benefits which he needs in order to pay or physical therapy and the adaptive equipment hat helps him to live in his own apartment.

James did not do very well in school and most of his teachers thought he was a slow learner. But in his last year of high school, a history teacher took a special interest in James. He spent extra time with him after school talking about ideas that seemed to wake James up. James began reading and studying on his own. For the last two years since leaving school, James has continued to read and study. He has learned that a local community college offers paralegal training and he is interested in going to school there. So far, James' vocational rehabili- tation counselor has not been much help. He says that James is needed badly in the sheltered workshop and that his tests don't indicate that James could succeed at legal work.

Recently James' next door neighbor has gotten interested in the problem. Frank is a college student himself and thinks that James should have the opportunity to study at the local college. Frank has started making phone calls to the counselor at the sheltered workshop and to the Department of Rehabili- tation. He is learning about IPPs, funding, and regulations. He is determined to succeed in gaining a chance for his friend.

Last week James and Frank decided to enroll to- gether in a night class at the college. The class is required for the legal secretary certificate. James plans to do well at the course and then take his good grades and report to his counselor. In the mean- time, Frank has made an appointment with a regional advocacy organization to learn more about his friend's rights.

CHAPTER III. WHAT CAN I DO TO HELP PEOPLE WITH SPECIAL NEEDS?

All people in our society have rights. Much of our legal and social system centers on the idea that each of us has basic rights as a citizen; people have a right to speak out, people have a right to their possessions and freedom from unreasonable invasion of their privacy, people cannot be deprived of life, liberty, or property without due process of law, people have the right to fair trial, etc.

Rights are not enforced by themselves. It takes self-assertion or the help of an organization to enforce our rights. For example, the Constitution guarantees all citizens the right to a fair trial, but it is difficult for people to get a fair trial without special legal assistance. The law now requires that people have an attorney to represent them. The right to an attorney was denied to most poor people until a prisoner in Florida, Mr. Gideon, asserted his right to a fair trial in a case which went to the Supreme Court. He needed the special assistance of a legal advocate and got one with the help of the Supreme Court. By winning, he established the right of all poor citizens to legal assistance in criminal cases. His case, Gideon vs. Gordon, is a good example of a person winning a battle to secure a right which is not self-enforcing. In order to enforce his right, Gideon needed extra help. By winning, he not only gained the right for himself, but assisted other people in securing their right to a fair trial.

Because most rights guaranteed by law are not self-enforcing, people need to learn to advocate for their rights. Advocacy means standing up for people's rights. It may mean standing up for your own rights, or it may mean standing up for others' rights. Advocacy can be as informal as a phone call to a key administrator or lobbying for the passage of legislation or as formal as a class action law suit. In general, advocacy embraces the idea that people with special needs, as well as all citizens, sometimes need to be assertive to secure their rights. Perhaps someday advocacy will not be so necessary. For now, since most people who have special needs suffer from exclusion and poor quality services, advocacy is essential.

Kinds of Advocacy

Self-advocacy. This is the most basic form of self-assertion to protect or gain rights. In self-advocacy, people who have special developmental needs speak for themselves by explaining their needs and desire for improved living conditions. People with special developmental needs learn to advocate for themselves in the same ways that other citizens learn to become more assertive. Training in asserting rights and speaking out in instances of discrimination can be a valuable tool for people with special needs. Even people with substantial disabilities can be taught rudimentary ways to communicate their needs and preferences. Increasingly, people with special developmental needs are joining together to form advocacy organizations such as People First of California and the Independent Living Center in California. These organizations offer great sources of strength for persons with special needs. People with special needs and their immediate relatives are often in the best position to speak out, but other citizens must also help.

Parent-to-Parent Advocacy. The parents of children with special needs and other close relatives, have firsthand experience with the impact of limited opportunities and services for their loved ones. Often the demands of having a child with special needs causes a great deal of stress and bewilderment for parents. Parent-to-parent advocacy means that experienced parents of children with special needs offer advice, counseling, and support to other parents. Parent organizations such as the California Society for Autistic Children, the Association for Retarded Citizens of California and the California Association for Neurologically Impaired Children offer parent-to-parent support. They are often extremely effective in improving services for people with special needs. Almost every major improvement in the law and in service delivery to people with special needs has come as the result of sustained effort by parent advocacy groups. If you know a young person with special developmental needs, you might ask if her parents have had contact with experienced parents of other children with special needs.

Person-to-Person Advocacy. People with special developmental needs who are successful often have a special friend who gives them extra help in daily life. More often than not, these friends are neither relatives nor professional service providers but instead are interested citizens who take a personal interest in helping a friend who has special needs.

James was the defensive captain of his high-school football team. His classmates called him "The Hulk" because of his 6'2", 190 pound size. During the last game of the year James was injured. He had to wear a cast and use crutches for the next three months. During that time a lot of his classmates razed him about being on crutches. They would jokingly call him names - "Hey, one leg, how's it going?"

James always ate lunch at the same time as a special education class at the high school. Whenever the special ed students came into the lunchroom, there were always a few of his friends who made nasty comments about the students with special needs. Sometimes they would even throw food at the handicapped students when the teacher was not looking. Because of his own experience with a temporary disability, James got interested in the special education students. He began going over and talking with them at lunch. One lunch hour he announced to the gang at his table that the special ed kids were his friends and that anyone who bad-mouthed them was bad-mouthing his friends. After that the rude remarks and the food throwing stopped. The special education teacher noticed that more students volunteered to be aides in his classroom. James was a person-to-person advocate. He took a few risks in order to help some friends with special needs and he provided a model for others to follow.

Jennette lives down the street from a group home for people with mild mental retardation. Every morning she rides to work with three of the group home residents who work in town. She noticed that one of her neighbors had trouble putting the right amount of change in the till. The bus driver often had to stop and help him select the right coins from a collection of pennies, dimes and quarters he carried in his pockets. Jennette got more interested in this young man when she struck up a conversation with him one morning about his work. She found out that he runs a big bailing machine at a sheltered workshop. He is obviously proud of his job. He also is a CB

radio buff in his leisure time. After thinking about it, Jennette offered to help her neighbor purchase a book of bus passes each month. She explained how to use the passes and went to the central bus station to assist him in purchasing the pass book. Once a month she goes with him and explains how much money he needs to pay in order to buy the pass book. Jennette is now thinking about giving her neighbor some lessons in coin and money identification. She has made an appointment with the staff of the group home to learn how to teach these skills. Jennette was pleased last week when two of the neighbors from the group home came over to help mow and weed her lawn.

Person-to-person advocates are ordinary citizens - high school students, neighbors, friends and professionals who take an interest in the life of a person with a special developmental need. They offer a little of their time and attention in order to help a friend be more independent and less alone. You could easily become a person-to-person advocate and make a difference in the life of a special friend.

Person-to-person advocacy does not require any special training or knowledge. It just requires good intentions, thoughtfulness and the willingness to take some risks in order to make friends with someone who may seem a little different than you until you get to know her.

If you become a person-to-person advocate you might become interested in learning more about how you can best help a special friend. Some of the ways that you would like to help may be more complicated than you expected. If you want to learn more about how to help a special friend deal with daily living, then you might want to become more committed to advocacy.

Citizen Advocacy. A citizen advocate is a concerned friend of a person with a special need. Ideally, citizen advocates are recruited trained and monitored by a citizen advocacy organization. Most areas of California, however, do not have Citizen Advocacy organizations. You

may, therefore, have to become a citizen advocate on your own. A citizen advocate speaks up, with, and for his friend with a special need. He might write a letter to a program administrator asking why his friend has been on a waiting list for so long. Or, he might attend a case management meeting with a social worker and express his concerns about his friend's housing or work situation.

A citizen advocate has to be informed. She must not only care about a friend with special needs, but she must also know what she is talking about. Ideally, she needs to know the legal rights of people with special needs, how the service system works, and who to talk to when a system fails to serve citizens appropriately.

A citizen advocate must be committed to his friend with special needs. Often change comes slowly and only after many meetings and letters. It does more harm than good to have an advocate start the process of advocating for a special friend and not carry through. Citizen advocates must be willing to go the whole distance.

A citizen advocate needs to have good communication and problem-solving skills. The best advocates know both how to listen carefully and how to help their friend present their case in speech and writing.

Ideally, a citizen advocate is a volunteer who is not paid by a service agency. It is difficult for an employee of a service agency to avoid conflicts of interest when advocating for a friend.

Group Advocacy. Many of the problems encountered by people with special needs are deeply rooted in our political and economic systems. For example, one problem faced by many people with special needs is that they lose Medicare benefits when they obtain a job and make even a modest living. Changing Medicare rules requires the efforts of groups which can advocate on a national scale. Obviously, one person speaking for another person is not enough to change a massive

Conflict of Interest: People working for an organization or making money from a service system may hesitate to criticize the organization because their own income or positions are involved. For example, it might be hard for the owners of a group home to admit that services in the home need to be improved, because they are financially and personally involved. This involvement is a conflict of interest.

system such as Medicare.

Group advocacy organizations work at the local, county, state and national levels. There are several effective advocacy organizations in California such as the State Council for Developmental Disabilities, The California Protection and Advocacy, Inc., the Area Boards, The Association of Retarded Citizens of California, People First, California Association for Autistic Citizens, and United Cerebral Palsy of California.

Group advocacy deals with system-wide problems. One such problem is the general lack of quality services for people with special needs. Too little money is allocated by the state and federal government each year to help local agencies start and maintain badly needed services. Another problem is that many existing services overly segregate the people they serve. Moreover, some services are dehumanizing and deliver inadequate care to clients. Because most services are organized on a large scale, group advocacy is needed. Also, group advocacy is needed because services are complicated and scattered. A person with special needs may be served by five different government programs at once and his well-being may be dependent upon each. The complex and the splintered nature of services can make individual advocacy ineffective for totally satisfying a person's needs. Finally, many advocacy issues require specially trained lawyers or psychologists to file briefs or testify at hearings. Advocacy groups can usually draw upon these resources more easily than individual advocates.

What Changes Are Needed?

This book has already described many of the changes needed in our present system of providing services for people with special developmental needs. Let's review some of the things that should be on the agenda of forward thinking advocacy groups:

Comprehensive Community-Based Services. Services for people with special needs should be available in each city, county and region of the state. No one should have to leave their home area to obtain a needed service. Services need to be comprehensive. It makes no sense to teach

a young person to work in high school and then provide no employment options for him as a young adult. It makes no sense to satisfy a few needs of parents of handicapped children but not provide the essential services needed by parents to keep their child at home.

Client Centered, Not Facility Centered Services. In our present system we often fit a client to an existing service. We ask "What services are available?" and place a person in the one which comes closest to meeting her needs. Usually, these services are centered in a facility such as a group home, state hospital, regional clinic, etc. Instead, we need services which go to a client. At one time, the services may be intensive and at another, they may involve only minor assistance.

Client Centered Services. If services were centered around clients' needs rather than facilities, they would be more flexible. The services provided to clients could change and develop as clients change and develop. For example, a client in a client-centered program might move from a state hospital to an apartment. During her first six months in the apartment, she might need total supervision in order to adjust to the many new demands of community living. She would have the constant assistance of a skill trainer and, perhaps, of a behavior management specialist. After she had learned more normal ways of behaving and independent living, the behavior management specialist would visit the apartment less and less and the skill trainer might see her less often. She would need less assistance to attend community recreation programs than she did during her first few months in the community. Next, she would have a vocational trainer work with her intensively during the day so that she could learn how to travel to a work site and learn to work. Later she would need only occasional follow-up visits from the vocational trainer. Once she had learned to live and work with some supervision, she might benefit from a structured adult education program at a local community college. As the client's skill level and needs changed, the services which she receives would also change. The current manner in which services are provided often lacks the flexibility necessary to provide services in this way.

Existing programs should not be faulted too much. It is important to remember that many dedicated people have fought to establish these programs and that the people who sponsor and operate them must struggle in the face of difficult circumstances. Most community service agencies are underpaid and understaffed. They must weather repeated changes in fiscal and social policy and operate with unskilled personnel.

Adequate Staffing and Funding. All community based programs must be funded at fair levels. Funding for staff and facilities should be comparable to funding for public schools. Most community programs have to operate on shoestring budgets. Resource shortages contribute to high staff turnovers, to instability and to the high mortality rate of community services.

In addition to fiscal poverty, programs lack trained staff. Community care providers in California are not required to learn any skills in order to care for people with special needs. The only monitoring of these providers is an inspection of their house to see that it is safe.

There are many important skills which care-providers, casemanagers, vocational trainers, recreational workers, etc. must know if they are to help people with special needs realize their full potential. The technology already exists to teach human services workers these skills. In a few places in the state there are organized programs to train personnel. But for the most part, workers in the field are untrained and their skills have been learned the hard way. Many times their skills are outdated.

Our knowledge about how to teach people with special needs has greatly increased over the past 10 years. Most workers in the field have had no way to keep up with the new methods and goals of instruction. Forward thinking advocates in California argue that we should have a competency-based training program for all people who work with persons who have special developmental needs. In this way, workers would need to show that they have the necessary skills to do a quality job before they go to work. We would not think of sending a child to a doctor who was not trained. But we routinely send our children to live 12 hours a day with untrained care providers.

Competency-based Training Program: A way to train people to do a job which makes sure that they really know the skills that are needed for that job. People who know the job well first list all the skills that a person does on the job. Students are then trained to perform each skill. Training continues until they can actually demonstrate accurate performance of each skill.

California has a wide-ranging system of higher education, including junior colleges in most counties and communities. This system is well equipped to begin offering training to those who work with citizens with special needs.

Re-allocation of Poorly Spent Resources. There are cost effective ways to establish comprehensive, personalized services with well-paid and well-trained personnel. Most human services resources now go to provide services in large, non-personalized settings. If non-personalized services were gradually converted into more home-like arrangements, the many trained workers and millions of dollars now spent on them could be transferred to support services which have wide-ranging benefits for our communities and for people with special needs. We have to learn how to effectively convert hospital services into stable community based services.

In-Home Support of Parents & Careproviders. Too few of our resources go to help parents keep children at home or to help community care providers to maintain persons with special developmental needs in quality, community-based care homes. In a sense, our current policy is anti-family in that all of the incentives are for placing a child out of his home. This system needs to be turned around so that a comprehensive set of family support services is offered to help parents assist their children with special developmental needs.

Employment for All Citizens. People with special developmental needs can work. They can do a variety of jobs which contribute to our economy and give them a valued role in our society. As long as we tolerate high levels of unemployment, people with special needs are likely to face a life of public support and be consumers of public resources rather than producers and contributors to society. At a policy level, the government could create incentives for employers to hire persons with special needs. Updated vocational training programs could place handicapped workers in normal competitive employment. Pilot projects around the country have demonstrated that even severely handicapped workers can succeed in competitive employment.

Protection and Advocacy. Services which monitor the quality of life of persons with special needs are for the most part lacking or understaffed in California. A broad-scale advocacy system is needed to ensure that people with special developmental needs have a voice. An area which particularly needs to be developed is protective services for people with special needs who live longer than their parents. Guardianship, conservatorship, and trust management services need to be better implemented.

Prevention. Half of the cases of developmental disabilities could be prevented through comprehensive programs. Prevention is an area which overlaps with many of our society's other major problems such as poverty, racism, lack of sufficient medical resources, and an unhealthy environment including extremely dangerous automobiles. Effective prevention efforts could prevent a great deal of human suffering. Preventive services benefit all citizens. A reduction in the number of people with special needs would make more resources available for those who do have special needs.

Co-ordination with Other Services. A theme of this book has been that all citizens at one time or another have special needs. To the extent that we improve conditions for people with lifelong needs, we are likely to help all citizens at times when they need extra help. Services for people who are disabled by accidents or strokes, people who are elderly and those who are mentally ill are presently separated and scattered. If we looked only at the needs of these citizens rather than their labels, we find that many services can be pooled. Elderly people who need help with independent living can be served by the same programs that teach living skills to people who have special needs for other reasons. Such coordination of services would show more citizens that helping one amongst us, helps all of us.

Advocacy Tactics That Work

We know enough about effective advocacy now to be able to identify tactics that work in improving service systems. There are tactics that work for citizen advocates and those that are effective for advocacy organizations.

Tactics for Citizen Advocacy. Effective advocates start by collecting necessary information before they act. They learn several important things. They learn what the legal rights are for people with special needs. They know who to call to get information or assistance. Moreover, along with knowing the law and important contact people, effective advocates learn what services are available in their area. Detailed information about how different agencies and meeting procedures work is also very useful. Successful advocates do their homework thoroughly.

Successful advocates also have several important communication skills. They learn to keep good records about their child or friend with special needs. They become skilled at writing letters and at making brief, clear phone calls about their concerns. Advocates learn to listen actively at meetings, to ask questions and to speak up. Taking notes can be an important skill. Public speaking is also a useful skill for effective advocates. Communication is the prime tool of a good advocate.

Some useful personal qualities of effective advocates are assertiveness, being prepared, persistance, a sense of humor and the ability to make compromises. It is also important to be diligent and to remain committed to change. Some of the interpersonal behaviors which do not help an advocate are shouting, getting angry, speaking in ignorance, treating others as enemies, trying to "get" others and calling names. A hostile, negative approach to advocacy is likely to backfire.

Most of the qualities, knowledge and skills which are important for successful advocates can be learned and taught. Active advocacy or parent groups can teach you the information and skills necessary to succeed as a change-maker.

Tactics for Group Advocacy. Group advocacy works on a broader scale than individual advocacy. It usually affects branches of government since government agencies usually control and shape services to people with special needs. Effective advocacy needs to work on all branches of government. Heavily relying on advocacy in only one of the three branches of government is not as effective as simultaneously pressing for change through the legislative, judiciary and executive branches of government. In recent years, many changes in services for people with special needs have originated from court cases. Many new rights have been defined. Class action lawsuits on behalf of

groups of people with special needs have effected changes in policy. However, these changes often are not implemented unless there is support from the legislative and executive branches of state and national governments. Letters and lobbying efforts in the state and national legislature have been effective tools of change. Also, the support of the executive branch has been important for many improvements for people with special needs. It is important that group advocacy efforts aim at all levels and all branches of government.

Control Mechanism-Pressure Points of Systems

Key leverage points exist for influencing the services for persons with special needs. These leverage points are the focal areas for prompting effective change. Advocates are likely to have maximum impact if they keep these points in mind:

Social Policy. One of the focal points for changing service systems are statements of social policy. These are often embodied in laws and in policy statement from the executive branch of government. California now has laws which state that comprehensive community services represent our social policy. Similarly, our national government has stated similar policies in the Rehabilitation Act of 1973 and Public Law 94-142. While good social policy is not sufficient to ensure change, it sets a climate for change and may contain some of the mechanisms for ensuring that change occurs.

Evaluation. Evaluation is the method by which a system monitors itself in order to see social policy is being implemented. An effective evaluation system is backed up with incentives and sanctions. For example, the Department of Social Services in California has a system of evaluating the physical setting of community care homes. It can levy fines and close down a facility if it is found to be unsafe or otherwise out of compliance with state regulations. But this system does evaluate the overall quality of life of people served in the care homes other than to see that they are safe and fed. The evaluation system does not look at the skills of the care provider, the skill training provided in the home, or the extent to

which opportunities for growth are provided to clients. Improvements in residential services to persons with special developmental needs in California must involve improvements in our evaluation system.

Training. Sound social policy and adequate evaluation systems are of little use unless the people who implement them are well trained. Trained personnel can make the difference between an outmoded program and a high quality one. Most direct care workers - as opposed to professional workers - in California are given little or no training. IF people were to be trained in normalization, personalization, and the developmental model, the delivery of services would be greatly improved.

Quality Standards. Quality standards set the tone for services in a system. Some states have set quality standards for special education programs which recommend the best current practice. The State of California has begun to establish quality standards for community programs through the use of an evaluation instrument called ANDI. These standards can have an important impact if they change opinions about what makes for quality services. Quality standards need to be backed up with incentives and sanctions. Good quality services need to be rewarded while poor quality services must be required to improve.

These four pressure points of a system can serve as the focus for effective change. Group advocacy organizations can be most effective by concentrating their efforts in these areas.

Personalization: The idea that services for people should be centered around individual needs, preferences, and outlook. Personalized services treat each person as unique and show regard for their needs and feelings. The opposite of personalized services are standardized, bureaucratic services in which everybody is treated the same.

Developmental Model: The idea that anybody can grow and learn at any stage of life. The developmental model is dynamic and includes the notion that one skill builds upon another. It implies that merely making a person physically comfortable is not enough; they should be given the chance to learn new skills and have new experiences.

Normalization: The principle that holds that people with special needs should be educated and served in ways that allow them to be a part in our mainstream society; to live, work, and play in our neighborhoods, factories, and parks alongside the rest of us.

ANDI: Stands for A Normalization and Development Instrument, and is used by the regional center system in the State of California to measure the quality of services in each region. ANDI is a way to take a careful look at community programs to see if they are based on the ideas of normalization, individualization, and the developmental model.

RALPH

Ralph was taken away from his parents when he was two years old because the welfare worker discovered he was malnourished and neglected. His parents have not contacted him since he was placed in the hospital.

Ralph now lives on a state hospital ward. There are thirty other children in the day area where he spends his time before and after school. There are no objects in the large room because some of the children are violent and throw things. A TV is suspended off the floor and a few of the children on the ward like to watch it. Ralph has a group leader who takes care of him and nine other children. Most of the children are not toilet trained and a few hurt themselves if they are not supervised. The group leader is hard-pressed to do much more than keep the children clean and safe. He is the second group leader so far this year and is growing pretty discouraged with his job.

Ralph lives in a world made up mostly of his own sensations. Most of the time he twirls, waves his head, flicks his fingers and spits. He likes to pick up small objects and put them in his ears and mouth. Ralph has never played a game or used a toy appropriately. He is not interested in people. When his group leader and teacher try to make friends with him he does not respond. He seems to like self-stimulating better than anything else.

Recently, Ralph has been enrolled in a special classroom for autistic children. The director of the program has had success in teaching children like Ralph, but he complains that more staff is needed to teach Ralph to be more normal and to help him have a more independent life.

The professionals who look in on Ralph agree that the odds are against him ever having a very normal life unless new programs are created to help children like Ralph.

CHAPTER IV. A GUIDE TO RESOURCES FOR CALIFORNIANS WITH SPECIAL DEVELOPMENTAL NEEDS

This chapter introduces the basic contact points in the service system for people with special needs. Because there are thousands of services and providers, this chapter does not try to list all of the organizations which provide services, just the main ones.

Regional Centers

Community services for people with developmental disabilities are accessible through California's system of Regional Centers. The state is divided into 21 regions which are administered by non-profit organizations, Regional Centers. These centers are funded by state and federal monies. They are the single point of entry for obtaining services. If you have a question or need a service, the chances are that someone at your local Regional Center office can help.

Regional Centers are responsible for diagnosing and evaluating people who are referred. Staff doctors, nurses, psychologists, and social workers evaluate persons to see if they qualify for services through the developmental services system. If a person is found eligible, a full scale assessment of their needs is completed. Based upon this assessment, an individual program plan is written.

The individual program plan, I.P.P., is an important document. If you are interested in a friend or relative with special developmental needs, be sure to understand what is on her I.P.P. The individual program plan is written each year. It is reviewed every three months to see if services are being provided and progress is being made. The I.P.P. should be written with goals that are aimed at increasing the individual's independence and productivity. Goals need to be written so that they can be measured. A goal which says "Jane will get better at walking" is not measurable. But one which says "Jane will increase the distance that she can walk from 10 yards to 50 yards" is measurable. An objective should also state how services will be provided. For example, the objective for Jane to improve her walking might say "Jane will

Individual Program Plan: State and federal laws require that clients who are served by the Regional Center system, special education programs, and vocational educational programs must have an individualized program. The program should state the client's needs and ways that the needs will be met. It should be written with clear objectives which can be measured. An I.P.P. must be reviewed regularly to make sure that it is being implemented and that it still represents the client's needs.

obtain one hour per week of physical therapy from Crippled Children's Services and will practice for 20 minutes each day under the supervision of her careprovider." When objectives are written in measurable ways, the people who are responsible for implementing them can be accountable. A person-to-person advocate can ask "Is this objective being carried out?" Because it is measurable, it is fairly easy to find out if Jane is getting one hour of physical therapy each week and if her careprovider practices with her. If not, the client's caseworker or some other advocate may be able to help solve the problems that are preventing the service from being provided.

Accountability: The concept that people's work can be measured in a fair way and that they can be held responsible for their work. When accountability is missing in complicated human service systems, it is impossible to find out who is responsible for getting something done and to reward the people who do good work and correct the ones who do not.

An I.P.P. must list all of the services which a a client needs. Many of these services can be provided by the Regional Center. Others are provided by other public and private agencies. There are many different ways that services are funded including payment by parents, Medi-Cal, other federal funds, and Regional Center funds. Most services are provided without charge when people cannot afford to pay.

Regional Centers are responsible for helping others to develop new community services. Resource development specialists at each center assist individuals and corporations who want to plan and open new services. Regional centers also evaluate the quality of the services in their region and inform people in their region about the needs and services available for people with special developmental needs, including information about the prevention of developmental disabilities.

Your local Regional Center is a key place if you are interested in helping someone with special needs. It can either provide services directly or it can direct you to an agency that can help. Regional Centers are responsible for intake and evaluation and also for making out-of-home placements of developmentally disabled persons. They also provide support services for people who live in their own homes. Most Regional Center employees specialize in case management. Case management involves tasks necessary to implementing a client's I.P.P.

The map on the next page is divided into service regions. You can locate your county on the map and determine which Regional Center serves your area. Below is a listing of the Centers:

1. North Coast Regional Center
   413 North State Street
   Ukiah, CA 94382
   (707) 462-3832
   Serves Del Norte, Humboldt, Mendocino, and Lake Counties

2. Far Northern Regional Center
   1505 East Street
   P.O. Box 878
   Redding, CA 96001
   (916) 243-4791
   Serves Siskiyou, Modoc, Trinity, Shasta, Lassen, Tehama, Glenn, Butte, and Plumas Counties

3. North Bay Regional Center
   1710 Soscol Avenue
   Napa, CA 94558
   (707) 252-0444
   Serves Sonoma, Napa, and Solano Counties

4. Alta California Regional Center
   4010 El Camino Avenue, Suite A
   Sacramento, CA 95821
   (916) 481-6101
   Serves Colusa, Sutter, Yuba, Sierra, Nevada, Yolo, Placer, El Dorado, Alpine, and Sacramento Counties

5. Golden Gate Regional Center
   100 Mission, Suite 400
   San Francisco, CA 94105
   (415) 546-9222
   Serves Marin, San Francisco, and San Mateo Counties

6. Regional Center of the East Bay
   2201 Broadway
   Oakland, CA 94612
   (415) 451-7232
   Serves Alameda and Contra Costa Counties

7. Valley Mountain Regional Center
   850 North Hunter Street
   Stockton, CA 95202
   (209) 948-0636
   Serves San Joaquin, Amador, Calaveras, Stanislaus, and Tuolumne Counties

8. San Andreas Regional Center
1270 Winchester Blvd.
P.O. Box 50002
San Jose, CA 95150
(408) 248-8500
Serves Santa Cruz, Santa Clara, Monterey, and San Benito Counties

9. Central Valley Regional Center
4747 North First St., Suite 195
Fresno, CA 93726
(209) 225-4500
Serves Merced, Mariposa, Madera, Fresno, Kings, and Tulare Counties

10. Inland Counties Developmental Disabilities Services
814 N. Arrowhead Avenue
P.O. Box 6127 (Zip 92412)
San Bernardino, CA 92401
(714) 888-6631
Serves San Bernardino, Riverside, Inyo and Mono Counties

11. Tri-Counties Regional Center
222 East Canon Perdido
Santa Barbara, CA 93101
(805) 963-6717
Serves San Luis Obispo. Santa Barbara, and Ventura Counties

12. Kern County Regional Center
501 40th Street
P.O. Box 2536
Bakersfield, CA 93301
(815) 327-8531
Serves Kern County

13. Regional Center of Orange County
Central Tower, Union Bank Square
500 South Main
Orange, CA 92668
(714) 973-1000
Serves Orange County

14. San Diego Regional Center
8001 Frost Street
San Diego, CA 92123
(714) 292-2996
Serves Imperial and San Diego Counties

Serving Los Angeles County:

15. Eastern Los Angeles Regional Center
801 S. Garfield Avenue, Suite 305
Alhambra, CA 91801
(213) 570-8620
Serves Alhambra, East Los Angeles, Northeast, Whittier

16. Frank D. Lanterman Regional Center
1605 West Olympic Blvd., Suite 600
Los Angeles, CA 90015
(213) 383-1300
Serves Central, Glendale, Hollywood-Wilshire, Pasadena

17. Harbor Regional Center
20620 S. Leapwood Avenue
Carson, CA 90746
(213) 323-3030
Serves Bellflower, Harbor, Long Beach, Torrance

18. North Los Angeles County Regional Center
14602 Victory Blvd.
Van Nuys, CA 91411
(213) 997-1311
Serves East Valley, San Fernando, West Valley

19. San Gabriel Valley Regional Center
1373 E. Center Court Drive
Covina, CA 91724
(213) 996-4417
Serves El Monte, Monrovia, Pomona

20. South Central Los Angeles Regional Center
2160 W. Adams Blvd.
Los Angeles, CA 90018
(213) 734-1884
Serves Compton, San Antonio, South, Southeast, Southwest

21. Western Regional Center
11300 S. LaCienega Blvd., Suite 400
Inglewood, CA 90304
(213) 670-7715
Serves Inglewood, Santa Monica, West

Regional Centers of California

1. North Coast
2. Far Northern
3. North Bay
4. Alta California
5. Golden Gate
6. East Bay
7. Valley Mountain
8. Loma Prieta
9. Central Valley
10. Inland Counties
11. Tri-Counties
12. Kern
13. Children's Hospital of L.A.
    East L.A.
    Harbor
    Kennedy
    North L.A.
    San Gabriel
    South Central L.A.
14. Orange County
15. San Diego

Area Boards

The Area Boards in California provide information, monitoring, and advocacy services. Area Board members are citizen volunteers that include persons with special developmental needs, parents of people with special needs, and other interested citizens. Area Boards employ small, well-trained professional staffs in each region of the state. They provide service information. Like the Regional Centers, Area Board staff can serve as an access point to the many services which exist in each region of the state.

The Area Boards' primary job is to serve as systemic advocates for people with special developmental needs, i.e., advocates when there are complaints about organization, such as the county education system, a community care home, or the vocational rehabilitation system. Area Board staff are usually very knowledgeable about group and citizen advocacy. They can help you learn to be a good advocate.

Area Boards are mandated by state law to monitor the quality of services in their region. They review local, state and federal regulations and laws which affect people with special needs. They investigate complaints about the quality of services in their region and work with other agencies to try to improve the quality of services. Finally, Area Boards keep tabs on what services are needed in their region and try to assist in program development.

Below is a list of Area Boards and a map showing which areas of the state are covered by each board:

Area Board I
P.O. Box 245
Ukiah, CA 95482
(707) 462-0518

Area Board II
2440 Main Street, Room 39
Red Bluff, CA 96080
(916) 527-0412

Area Board III
1722 J Street, Suite 321
Sacramento, CA 95814
(916) 322-6078

Area Board IV
1700 Second Street, Suite 212
Napa, CA 94558
(707) 252-6644

Area Board V
436 14th Street, Suite 1216
Oakland, CA 94612
(415) 464-0439

Area Board VI
1230 13th Street, Suite B
Modesto, CA 95354
(209) 526-6840

Area Board VII
Agnews Residential Facility
San Jose, CA 95114
(408) 988-0111

Area Board VIII
546 West Shields, Suite A
Fresno, CA 93705
(209) 222-2496

Area Board IX
3704 State Street, Suite 310
Santa Barbara, CA 93105
(805) 682-8374

Area Board X
1300 West Olympic Blvd., Suite 300
Los Angeles, CA 90015
(213) 736-3402

Area Board XI
250 S. El Camino Real, Suite 110
Tustin, CA 92680
(714) 731-4787

Area Board XII
1960 Chicago AVenue, Suite E-8
Riverside, CA 92507
(714) 781-0722

Area Board XIII
6060 Mission Gorge Road, Suite 208
San Diego, CA 92120
(714) 563-1523

DEVELOPMENTAL DISABILITIES
AREA BOARDS

Individual Advocacy

If a relative or friend with special developmental needs encounters discriminatory treatment, lack of services, poor quality services, or a violation of her legal rights, the help of a full-time advocate may be required. Along with Area Boards, there are other professional advocates available. As mentioned above, Area Boards primarily work on group advocacy and usually do not address the problems of individuals unless a complaint deals with some weakness of an existing service program. There are, however, some organizations which do provide individual advocacy services.

Regional Center Advocacy Services. Each Regional Center has at least one paid staff member who serves as a client's rights advocate. This person is responsible for seeing that the legal and ethical rights of regional center clients are respected. A client's rights advocate investigates complaints of abuses of client's rights and provides assistance in correcting violations.

Protection and Advocacy, Inc. This advocacy organization is established through federal funds to investigate complaints that the rights of an individual with special needs have been violated. Their board of directors consists of persons with special needs, their families, people from other advocacy organizations in the state, and people from service organizations.

There are many situations in which you might call Protection and Advocacy, Inc. for help. For example, if a relative or friend is being denied a service because he is not judged to meet eligibility requirements, you might call to be sure that the denial of services is appropriate. Moreover, if a friend or relative is being mistreated or cannot find a needed service, you can turn to Protection and Advocacy, Inc. for advice and help.

Protection and Advocacy, Inc. has a toll-free number which you can use anywhere in California: 800-952-5746. You can write to them at:

Protection and Advocacy, Inc.
1400 K Street, Suite 307
Sacramento, California 95814

Parent-to-Parent Advocacy

Parents often find their best source of information and emotional support comes from other parents who have experienced similar problems. A national agency called Closer Look has been set up in order to serve as an information center for parents who would like to share ideas and support with other parents. Closer Look can tell you where to find a parent group in your locale. Closer Look can be contacted at:

Closer Look
P.O. Box 1492
Washington, D.C. 22013

Special Education Services

By federal and state law, your county or local school system is required to provide a free, appropriate education to all children, including those with handicapping conditions. Educational services are available from infancy through adulthood in some areas of the state. If you would like to get information about the educational programs which are available in your area, contact the office of the county Superintendent of Schools. The county superintendent will either know what services are available or will direct you to the best local agency to answer your questions. If you reach a dead end at the local level, contact a special education consultant at the State Department of Education. The best way to track down the consultant who works in your county is to call the State Office of Special Education at 916/445-4036.

Vocational Rehabilitation Services

If you need information or have a complaint regarding vocational services, you can get assistance from the local office of the California State Department of Rehabilitation. If you have trouble locating the local office for your area, you can telephone 916/322-8500. The Department of Rehabilitation is responsible to help people gain skills that make them employable and to help persons find jobs. The department places many individuals in sheltered workshop programs and in competitive employment. It also evaluates clients' needs and writes individual program plans.

Consumer Organizations

There are several statewide self-help organizations which can give information and support, and

connect you to local people who have similar interests. These organizations promote the interests of persons with special needs. They can be an excellent source of information and assistance. There are many such voluntary organizations. A few of the largest ones, with statewide offices, are listed here:

Association for Retarded Citizens - California. This organization has 66 local chapters throughout the state. These chapters advocate for state and local laws that will benefit citizens with mental retardation. They are also involved in prevention campaigns and provide information to promote cooperation between programs that serve people with special needs. Their interests include all facets of programming for persons with mental retardation, including education, housing, jobs, protection and advocacy, and guardianship-conservatorhsip programs. Most local chapters sponsor direct service programs. You can locate the nearest ARC to your home by calling ARC California at 916/441-3522 or writing:

Association for Retarded Citizens - California
1414 K Street, Suite 300
Sacramento, CA 95814

California Association for Neurologically Handicapped Children. This is a statewide organization for children and adults with learning disabilities. It has many local chapters. It lobbies on the state level and publishes a monthly newsletter. It advocates on issues for people with learning disabilities. The address of the main office is:

CANHC
P.O. Box 61067
Sacramento, CA 95860

California Epilepsy Society. This organization disseminates information about epilepsy and convulsive disorders. It is interested in educating the public about epilepsy in order to dispel some of the prevalent stereotypes and stigmas that are sometimes ascribed to people with epilepsy. The California Epilepsy Society promotes better laws for persons with epilepsy and is a good source of information about treatment programs and support groups in your area.

California Society for Autistic Children (C.S.A.C.). The Society serves parents and friends of persons with autism. They serve as a clearinghouse for information about services in your area and can connect you with other interested people. The Society can be contacted at:

National Society for Autistic Children
1234 Massachusetts Avenue Northwest, Suite 1017
Washington, D.C. 20005

People First of California. People First is a nonprofit corporation whose membership consists of persons who are labeled "mentally retarded." The organization's primary purpose is to promote self-advocacy efforts by and for persons who are considered to be mentally retarded. The headquarters of People First is located in Mill Valley and its local chapters extend from Eureka to San Diego. You may contact People First as follows:

People First, Inc.
70 Lomita Drive Building No. 2
Mill Valley, California 94941
(415) 388-9200

United Cerebral Palsy Association of California. This organization serves the interests of people with cerebral palsy. Local chapters sponsor a variety of programs including apartment programs, recreation activities, workshops, and independent living programs. They also work as advocates for persons with cerebral palsy. Local chapters are an excellent contact point if you are interested in getting help for a person with cerebral palsy. They can be identified by contacting:

United Cerebral Palsy
120 N. El Camino Real
San Mateo, CA 94401
415-348-1641

Summary

The resources listed above can help you find others with similar concerns in your area. By sharing information and asking questions you can go a long way toward becoming an effective advocate, parent, or friend of a person with a special developmental need.

SALLY AND ELAINE

Sally is Elaine's mother. She has recently been divorced after a marriage of 13 years. Sally now has custody of Elaine. The intensive care that Elaine needs was one of the causes of the divorce. Elaine is now 12. She uses a wheelchair to get around. She is not toilet trained and needs help with eating each day. She also occasionally has uncontrolled seizures. When these happen, Elaine has to go to the hospital emergency room. Although these hospital trips are almost routine for Sally by now, they are always exhausting.

Sally has learned a great deal about services for people with special developmental needs since Elaine was born. She finished a Master's degree program and then held jobs at a state hospital and at a regional center. After working on a hospital ward for children with needs similar to Elaine's, Sally determined to find a more personalized way of living for her daughter in her adult years.

Recently a training home for people with special developmental needs has opened in Sally's region. The home is meant to train people to live more independently. A staff teaches such skills as independent eating, grooming, toileting, and leisure time skills. When Elaine first went to live in the training home, her mother was uncomfortable with how the staff related to Elaine. However, she learned more about their training system and the staff responded to her concerns. She now is happy that Elaine will be in the home for the year. Elaine has made some small progress at the home but has not yet learned proper toileting skills. Elaine's doctors are not sure if this is possible. Sally is planning to have Elaine come back home after she has been in the training home for one year. She is worried about how hard it will be to take care of Elaine now that she is a single parent.

The people who teach and take care of Elaine are very fond of her. She has an engaging smile and loves attention from the people around her. She returns their affection. All of these people who know Sally and Elaine wonder what will become of them.

CHAPTER V. CONCLUSION

This book has provided a quick look at the world of people who have special developmental needs. It has pointed out that all of us have special needs on occasion. We all need individual attention in order to do our best as students, workers, and citizens. Moreover, at some time during our lives, most of us will need special assistance because of illness, stress, injury, or old age.

Some citizens need more help than most of us due to a physical or mental challenge. There are many causes for these challenges. This book has emphasized the common needs shared by all people: self-care, communication, mobility, independent living, learning, and economic self-sufficiency.

Problems exist due to the ways that we presently give people extra help. People with special needs have been viewed as deviant. They have been seen as objects of pity or scorn rather than as friends, neighbors, and citizens. They have been segregated in large congregate living arrangements and isolated in sheltered workshops. Services have been poorly funded and workers have been undertrained and underpaid. A lot of money and energy have been wasted by providing services too late and in the wrong way. If we put more effort into preventing handicapping conditions, the savings in cost and human suffering could be enormous. If we support the families of children with special needs, we help keep children in their natural families. If we teach children and young adults useful skills, we prepare them for independent living. If we assist people with special needs to obtain and keep competitive jobs, we gain a huge economic and social resource. Right now we are often penny wise and pound foolish--saving money in the short run in ways that cost us enormously in the future.

This book has reviewed important ideas that are shaping quality human services:

Normalization. This principle holds that people with special needs should be educated and served in ways that allow them to be a part of mainstream society; to live, work, and play in our neighborhoods, factories, and parks alongside the rest of us.

Developmental Model. This principle holds that all human beings grow and learn throughout life, no matter how severely they are disabled or where their starting point may be. This viewpoint suggests that good services teach new skills and concepts.

Personalization. No two people are alike. The range of differences among people with special needs is huge. One person may need a Braille law book while another may need instruction on how to brush his teeth. One may enjoy bowling while another prefers going to the horse track or the ballet. People with special needs are, first and foremost, people.

This book briefly described some of the services that are now available for persons with special developmental needs. It described residential services: community care homes, group homes, large board and care homes, and institutions. It also described some ways these services need to be improved: better financial support, more training for care providers, and more training and activities for clients. It emphasized the need to help families keep their disabled relative at home, and stressed the need to make services more flexible.

Educational services for people with special needs were also discussed. It is important to prepare students for daily living in integrated communities. Such an education teaches work, leisure, and independent living skills and helps students develop social skills necessary to act as fellow workers and neighbors.

Vocational services for people with special needs were also briefly explained. The book mentioned that every dollar we spend on vocational rehabilitation is repaid to society from two to seven times due to taxes subsequently paid by trainees. It explained the sad fact that most people with special needs cannot find gainful employment and that if they do work they generally receive only subminimal wages in sheltered workshops. Most citizens with special needs can work. They can do complicated, useful work which benefits society.

This book has looked at some of the many ways that you can help people with special needs. It has

emphasized that some of the most important help that you can provide is simple and straightforward, requiring only your generosity and common sense. People with special needs need your friendship, companionship, warmth, and help with solving some of the difficulties encountered in daily living. Providing this help can offer you many rich rewards.

More formal ways of helping people with special needs have also been presented. Citizen advocacy has been briefly explained. Citizen advocates learn about the rights and services available to citizens with special needs. They use their knowledge and communication skills to obtain better services and conditions for people who may not be able to speak for themselves. Group advocacy organizations work on a larger scale. They act on systemic pressure points to open the way for large scale changes. Group advocacy has made a big difference in the lives of many citizens during the past 30 years.

This book also has included a brief resource guide. The chapter on resources tells you where to go in order to either secure services for a person with special needs or to find where to get services. There are thousands of organizations and programs that serve people with special needs. Rather than listing these organizations, this book has provided a guide to entering the system. The people at the organizations listed in Chapter IV can help interested persons get involved in hleping others.

Finally, this book is meant to stress how important you can be. The lives of many people with special needs have greatly improved over the past 30 years. We have a long way to go, however, before the ideal of full citizenship is realized by all people with disabilities in our country. Interested individuals like you can make a big difference. Maybe you have seen The Miracle Worker, the story of Ann Sullivan and Helen Keller. It is a good example of how the efforts of one person can open up a whole universe for another person.

Only a few years ago millions of children were completely excluded from public school education. Now, as a result of the advocacy efforts of parents, professionals, and other interested citizens, most children who need special education receive instruction

in public schools. Similarly, there have been wonderful advances in our knowledge about how to teach people with special needs. Only a few years ago people believed that autism was a hopeless condition. Persons with autism were commonly condemned to live in extreme isolation. The use of new teaching techniques has shown that autistic people can learn, grow, work, and live in the community. Similarly, new adaptive equipment and teaching aids have opened up whole new worlds for many people with sensory and physical handicaps. The invention of portable communication equipment has allowed hundreds of people who could never communicate to express their needs, wants, hopes and fears.

The job of improving human services is enormous but much has already been accomplished. You can make a great contribution. We will all reap the benefits.

BIBLIOGRAPHY

Adams, S., & Rullman. Games, sports and exercises for the physically handicapped. Philadelphia: Fea & Febigger, 1975.

Amary, I.B. Creative recreation for the mentally retarded. Springfield: C.C. Thomas, 1975.

Apolloni, T., Cappuccilli, J., & Cooke, T.P. (Eds.) Achievements in residential services for persons with disabilities: Toward excellence. Baltimore: University Park Press, 1977.

Apolloni, T., Cooke, T.P., & Bronston, W. (Eds.) Consumer unity: New platforms for progress in the 1980s. Sacramento: California Department of Rehabilitation, 1981.

Baker, B.L., Seltzer, G.B., & Seltzer, M.S. As close as possible: Community residences for retarded adults. Boston: Little, Nrown & Company, 1977.

Baron, R.C., Rutman, I.D., & Klaczynska, B. (Eds.) The community imperative: Proceedings of a national conference on overcoming public opposition to community care for the mentally ill. Philadelphia: Horizon House Institute, 1980.

Bass, M.A., Gordon, S., & Kempton, W. Love, sex, and birth control for the mentally retarded. Philadelphia: Planned Parenthood Association fo Southeastern Pennsylvania, 1971.

Biklen, D. Let our children go. Syracuse, NY: Human Policy Press, 1974.

Blatt, B. Christmas in purgatory: A photographic essay on institutions. Syracuse, NY: University Training Institute for Human Service Planning Leadership & Change Agentry.

Bradley, V.J. Deinstitutionalization of developmentally disabled persons. Baltimore: University Park Press, 1978.

California Instructional Television Consortium. Way to go. Baltimore: University Park Press, 1978.

De Jardins, Charlotte. How to organize an effective parent group and move bureaucracies. Chicago: Coordinating Council for Handicapped Children, 1971.

DuRand, J., & Neufeldt, A.H. Comprehensive vocational service systems. (NIMR Monograph No. 4). Toronto: National Institute on Mental Retardation, 1975.

Fisher, H., Krajicek, & Brothick. Sex education for the developmentally disabled: A guide for parents, teachers, and professionals. Boston: University Park Press, 1974.

Flynn, R.J., & Nitsch, K.E. Normalization, social integration, and community services. Baltimore: University Park Press, 1980.

Human Services Associates. Personalized living: Homes for Californians with special developmental needs. Sacramento: California State Council on Developmental Disabilities, 1979.

Moise, L. As up we grew with Barbara. Minneapolis: Dillon Press, Inc., 1980.

Moise, L. Will the real advocate for retarded persons please stand up? National Association for Retarded Citizens.

Nelson, R. Creating community acceptance for handicapped people. Springfield, Illinois: Charles C. Thomas, 1978.

Perske, R. (Ed.) Improving the quality of life: A symposium on normalization and integration. Arlington, TX: National Association for Retarded Citizens, 1977.

Perske, R. New life in the neighborhood. Nashville: Abingdon, 1980.

Perske, R., Clifton, A., McLean, B., & Stein, J.I. Mealtimes for severely and profoundly handicapped persons. Baltimore: University Park Press, 1977.

President's Committee on Mental Retardation. Changing patterns in residential services for the mentally retarded. Washington, D.C.: PCMR, 1976.

President's Committee on Mental Retardation. Mental retardation: The leading edge. Washington, D.C.: U.S. Government Printing Office, 1978.

President's Committee on Mental Retardation. New neighbors: The retarded citizen in quest of a home. Washington, D.C.: PCMR, 1974.

Pieper, B. Start organizing from scratch--SOS for new parents. Syracuse: Center on Human Polidy, 1975.

Research and Training Center in Mental Retardation. Citizen Advocacy Resources. Lubbock, Texas: Texas Tech University, 1979.

Roos, P., McCann, B., & Addison, M.R. Shaping the future: Community-based residential services and facilities for mentally retarded people. Baltimore: University Press, 1950.

Wiegerink, R., & Pelosi, J.W. Developmental disabilities: The DD movement. Baltimore: Paul H. Brookes, 1979.

Wolfensberger, W. Normalization: The principle of normalization in human services. Toronto: National Institute on Mental Retardation, 1972.

Wolfensberger, W. The origin and nature of our institutional models. Syracuse, NY: Human Policy Press, 1975.